# A PUBLIC HEALTH APPROACH TO ALZHEIMER'S AND OTHER DEMENTIAS

## **MODULE 2:**

## ALZHEIMER'S AND OTHER DEMENTIAS—THE BASICS









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#### **ABOUT MODULE 2**

This module is part of the Alzheimer's Association curriculum, *A Public Health Approach to Alzheimer's and Other Dementias*. Developed as part of a cooperative agreement with CDC's Healthy Aging Program, and in partnership with Emory University's Rollins School of Public Health, this curriculum addresses cognitive health, cognitive impairment, and Alzheimer's disease and is for use by undergraduate faculty in schools and programs of public health.

**Module 2: Alzheimer's and Other Dementias – The Basics** provides background information on Alzheimer's and other dementias. It lays a foundation for what cognitive health is and how changes within the brain may lead to cognitive aging, cognitive impairment, and Alzheimer's and other dementias.

The module then shifts to focus more specifically on Alzheimer's disease. Learners gain a general understanding about the three stages of Alzheimer's disease, risk factors, and how the disease is diagnosed and treated. The module also addresses unique aspects of Alzheimer's disease (including financial hardship, stigma, and vulnerability to abuse), and the role and burden of caregivers.

#### Module 2 contains the following topics:

- Cognitive health
- Dementia
- Alzheimer's disease
- Risk factors
- Treatment & management
- Caregivers
- Unique aspects

#### **LEARNING OBJECTIVES**

At the end of *Module 2: Alzheimer's and Other Dementias – The Basics* students will be able to:

- Define cognitive health.
- Define and differentiate between dementia and Alzheimer's disease.
- List at least five common symptoms of Alzheimer's disease.
- Describe the changes that occur during the course of Alzheimer's disease.

#### Module 2: Alzheimer's and Other Dementias – The Basics

- Identify at least three risk factors associated with Alzheimer's disease.
- Describe the role of caregivers in the care of someone with Alzheimer's disease.

#### **COMPETENCIES**

Module 2 promotes basic learning that supports the development of certain competencies:

#### **Association for Gerontology in Higher Education (AGHE):**

- 1.2.1 Distinguish normal biological aging changes from pathology including genetic factors.
- 1.3.3 Demonstrate knowledge of signs, symptoms, and impact of common cognitive and mental health problems in late life (e.g., dementia, depression, grief, anxiety).
- 1.2.4 Recognize common late-life syndromes and diseases and their related biopsycho-social risk and protective factors.

#### Association of Schools and Programs of Public Health (ASPPH):

 Domain 1: Describe risk factors and modes of transmission for infectious and chronic diseases and how these diseases affect both personal and population health.

#### National Association of Chronic Disease Directors (NACDD):

- Domain 7: Discuss the underlying causes and management of chronic diseases, including behavioral, medical, genetic, environmental and social factors.
- Domain 7: Articulate key chronic disease issues.
- Domain 7: Describe socioeconomic and behavioral determinants of health disparities.

#### National Commission for Health Education Credentialing, Inc. (NCHEC):

 7.1.1 Identify current and emerging issues that may influence health and health education

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#### LAYOUT OF MODULE 2 FACULTY GUIDE

This guide is laid out in the following sections:

- Slide guide with talking points
- Sample test questions
- Case studies
- Video resources

Note: Some slides in this module duplicate content from other modules and may be removed as needed.

#### **HOW TO USE THE MATERIALS**

- ✓ This module is one of four modules in this curriculum that were designed for use either as a set or as stand-alone modules.
- ✓ Users are free to make changes to the materials to fit their needs, including: adding, modifying or removing content, graphics, talking points, discussion questions or learning activities.
- ✓ The Faculty Guide for each module includes a slide guide that contains the information as presented in the slide, talking points, space for presenter notes, and references.
- ✓ The talking points included in the Faculty Guide should not be read word for word; each presenter should review the materials before delivering the material to ensure familiarity and deliver the information in his/her own style.
- ✓ Delivery time will generally be 60-90 minutes per module, depending on class engagement, presenter style, and the addition or elimination of any content, discussion questions, or learning activities.
- ✓ Discussion questions are included in the slide deck of each module. These may be modified or removed at the discretion of the presenter. Questions may also be used for other activities such as small group discussion or individual writing assignments.
- ✓ Video resources, a list of articles and case studies are also included to help in learning more about the topics presented in each module.
- ✓ Test questions are provided with each module as an additional resource for faculty.
- ✓ All materials are 508 compliant. (Note: if changes are made to the curriculum, it is recommended that changes continue to follow 508 compliance guidelines. For more information on 508 compliance visit the Department of Health and Human Services website: http://www.hhs.gov/web/section-508/making-files-accessible/checklist/)

#### STUDENT ENGAGEMENT OPTIONS

In addition to the PowerPoint slide deck and guide, there are additional resources included in this guide. These resources are designed to increase student engagement and enhance understanding of the concepts covered in this module. Following the slide guide, there is a series of case studies and a list of video resources. It is recommended that the presenter review these resources to determine if these additional materials would be useful in illustrating the concepts covered in the module.

#### **DISCUSSION QUESTIONS**

The following discussion questions are included in the slide deck:

- What is cognitive health? (Slide 5)
- What are the characteristics of Alzheimer's disease? (Slide 20)

#### **LEARNING ACTIVITIES**

The following learning activities may be used or adapted to enhance student learning:

- Research personal perspectives on Alzheimer's and dementia. What happens to someone's mind, lifestyle, and relationships, in their own words?
- Describe the physiological changes to the brain that occur with Alzheimer's disease. What do scientists know about how the disease develops? What are current areas of focus in research?
- Conduct a short interview with 4-5 adults over the age of 50. Develop and ask
  questions related to interest and concerns about participating in clinical trials
  related to Alzheimer's disease. Summarize their responses and describe
  implications for a campaign to promote clinical trials participation.

#### **ADDITIONAL READING**

- Alzheimer's Association. 2016. Overview of Alzheimer's Disease (pp. 5-14)
   In Alzheimer's Disease Facts and Figures. Chicago, IL: Alzheimer's Association.
   <a href="http://www.alz.org/facts">http://www.alz.org/facts</a>
- The NIH Alzheimer's Disease Education and Referral Center:
   Information about symptoms at each stage of Alzheimer's and how the disease progresses. <a href="https://www.nia.nih.gov/alzheimers">https://www.nia.nih.gov/alzheimers</a>
- National Institute on Aging. 2008. Alzheimer's Disease: Unraveling the Mystery.
   NIH Publication No. 08-3782. Washington, DC: US Department of Health and Human Services.
  - https://www.nia.nih.gov/sites/default/files/alzheimers disease unraveling the mystery 2.pdf

## **SLIDE GUIDE**

This slide guide accompanies the PowerPoint presentation for this module. The right margin has been widened to allow the presenter to write notes.

#### **SLIDE 1:**

Module 2: Alzheimer's and Other Dementias – The Basics

#### **TALKING POINTS:**

This presentation entitled, **Alzheimer's and Other Dementias** – **The Basics** is part of a curriculum for public health students entitled, *A Public Health Approach to Alzheimer's and Other Dementias*. It was developed by the Emory Centers for Training and Technical Assistance for the Alzheimer's Association with funding from the Centers for Disease Control and Prevention.

This module provides background information on cognitive health, cognitive impairment, dementia, and Alzheimer's disease. It provides essential information on Alzheimer's disease, including what is known about its causes, its progression, risk factors, and care.

#### SLIDE 2:

## **Learning Objectives**

- Define cognitive health
- Define and differentiate between dementia and Alzheimer's
- List at least 5 common symptoms of Alzheimer's
- Describe the changes that occur during the course of Alzheimer's
- Identify at least 3 risk factors associated with Alzheimer's
- Describe the role of caregivers

#### **TALKING POINTS:**

By the end of the presentation, you will be able to:

- Define cognitive health
- Define and differentiate between dementia and Alzheimer's
- List at least 5 common symptoms of Alzheimer's
- Describe the changes that occur during the course of Alzheimer's
- Identify at least 3 risk factors associated with Alzheimer's
- Describe the role of caregivers

#### SLIDE 3:

#### **Competencies:**

#### **Association for Gerontology in Higher Education (AGHE):**

- 1.2.1 Distinguish normal biological aging changes from pathology including genetic factors.
- 1.3.3 Demonstrate knowledge of signs, symptoms, and impact of common cognitive and mental health problems in late life (e.g., dementia, depression, grief, anxiety).
- 1.2.4 Recognize common late-life syndromes and diseases and their related bio-psycho-social risk and protective factors.

## Association of Schools and Programs of Public Health (ASPPH):

 Domain 1: Describe risk factors and modes of transmission for infectious and chronic diseases and how these diseases affect both personal and population health.

## **TALKING POINTS:** (this slide can be edited as needed or removed)

The content in this presentation supports the development of the following competencies:

### <u>Association for Gerontology in Higher Education (AGHE)</u>:

- 1.2.1 Distinguish normal biological aging changes from pathology including genetic factors.
- 1.3.3 Demonstrate knowledge of signs, symptoms, and impact of common cognitive and mental health problems in late life (e.g., dementia, depression, grief, anxiety).
- 1.2.4 Recognize common late-life syndromes and diseases and their related bio-psycho-social risk and protective factors.

### Module 2: Alzheimer's and Other Dementias – The Basics

# <u>Association of Schools and Programs of Public Health</u> (ASPPH):

• Domain 1: Describe risk factors and modes of transmission for infectious and chronic diseases and how these diseases affect both personal and population health.

#### SLIDE 4:

#### **Competencies cont.:**

#### **National Association of Chronic Disease Directors (NACDD):**

- Domain 7: Discuss the underlying causes and management of chronic diseases, including behavioral, medical, genetic, environmental and social factors.
- Domain 7: Articulate key chronic disease issues.
- Domain 7: Describe socioeconomic and behavioral determinants of health disparities.

## National Commission for Health Education Credentialing, Inc. (NCHEC):

 7.1.1 Identify current and emerging issues that may influence health and health education

## TALKING POINTS: (this slide can be edited as needed or removed)

#### National Association of Chronic Disease Directors (NACDD):

- Domain 7: Discuss the underlying causes and management of chronic diseases, including behavioral, medical, genetic, environmental and social factors.
- Domain 7: Articulate key chronic disease issues.
- Domain 7: Describe socioeconomic and behavioral determinants of health disparities.

# National Commission for Health Education Credentialing, Inc. (NCHEC):

• 7.1.1 Identify current and emerging issues that may influence health and health education

SLIDE 5:
Discussion Question
What is cognitive health?

**Ask:** What is cognitive health?

Open responses.

#### SLIDE 6:

## **Cognitive Health1**

- Cognition: the ability to think, learn, and remember
- Cognitive health continuum: "optimal functioning" to severe disability
- Linked to brain health

#### **TALKING POINTS:**

To understand what happens to a person when he or she develops Alzheimer's or dementia, it is helpful to first consider **cognitive health**.

**Cognition** refers to the ability to think, learn, and remember.

**Cognitive health** can be viewed along a continuum. At one end is "optimal functioning," which refers to a healthy brain that can perform the following mental processes:

- Ability to learn new things
- Intuition
- Judgment
- Language
- Remembering

At the other end of the spectrum are people with severe Alzheimer's, dementia, and other brain injuries that render that person unable to function cognitively. Cognitive health is linked to brain **health** in terms of the physiologic health of the brain and overall functioning.

Image source: National Institute on Aging

**FACULTY GUIDE** 

<sup>&</sup>lt;sup>1</sup> Centers for Disease Control and Prevention, Division of Healthy Aging. What is a Healthy Brain? New Research Explores Perceptions of Cognitive Health Among Diverse Older Adults.

#### SLIDE 7:

## Cognitive Aging<sup>2,3</sup>

- The brain changes as it ages
- Increase in wisdom and expertise
- Speed of processing, making decisions, remembering may decline
- Normal part of aging

#### **TALKING POINTS:**

Like other organs in the human body, the brain changes as it ages. Physical structures in the brain change, and its ability to carry out various functions tends to decline.

Wisdom and expertise can increase with age, while the speed of processing information, making decisions, and remembering certain things can decline.

This process is known as **cognitive aging** – a decline in memory, decision-making, processing speed, and learning. For example, a person might have trouble following a recipe, remembering certain words, or finding common items such as glasses or keys.

These changes are considered a **normal part of aging**, are different for different people, and may vary from day to day.

*Image source:* Copyrighted image; used with permission from the Alzheimer's Association

 $<sup>^2</sup>$  Institute of Medicine. (2015) *Cognitive Aging: Progress in Understanding and Opportunities for Action*.

<sup>&</sup>lt;sup>3</sup> National Institute on Aging. (2013) *Understanding Memory Loss: What To Do When you Have Trouble Remembering*.

#### SLIDE 8:

## Mild Cognitive Impairment (MCI)<sup>4,5</sup>

- Difficulty with cognitive processes
- Not severe enough to interfere with daily life
- Increased risk of Alzheimer's or dementia
- May be caused by external factors (vitamin B12 deficiency, depression)

#### **TALKING POINTS:**

Mild cognitive impairment (MCI) is a condition in which people have more memory or other thinking problems than normal for their age, but their symptoms are **not severe** enough to interfere with daily life or their ability to function independently.

Symptoms of MCI may include: forgetting important information that he or she would previously have easily recalled (such as appointments, conversations, or recent events), or a decreased ability to make sound decisions, judge the time or sequence of steps needed to complete a complex task, or have trouble with visual perception.

A person with MCI is at an **increased risk** of developing Alzheimer's or other dementia.

In some cases, however, the condition may be caused by **external factors**, such as medication, vitamin B12 deficiency, and depression. In these cases, the condition can be reversed, reverse on its own, or remain stable.

<sup>&</sup>lt;sup>4</sup> Alzheimer's Association. (2012) *Mild Cognitive Impairment*.

<sup>&</sup>lt;sup>5</sup> National Institute on Aging, *About Alzheimer's Disease: Mild Cognitive Impairment*. Accessed June 10, 2015 from website: <a href="https://www.nia.nih.gov/alzheimers/topics/mild-cognitive-impairment">https://www.nia.nih.gov/alzheimers/topics/mild-cognitive-impairment</a>.

### SLIDE 9:

## **Cognitive Impairment<sup>6</sup>**

- Difficulty with cognitive processes that affect everyday life
- Spans wide range of functioning
- Can occur as a result of Alzheimer's, dementia, stroke, traumatic brain injury

#### **TALKING POINTS:**

Further along the cognitive health continuum is **cognitive impairment**.

When a person has trouble with cognitive processes that begin to affect the things he or she does in everyday life, it is often referred to as **cognitive impairment**.

Cognitive impairment spans a **wide range of functioning.** It can occur as a result of Alzheimer's or other dementias, or with other conditions such as stroke and traumatic brain injury.

*Image source:* National Cancer Institute, NCI Visuals Online, Daniel Sone (Photographer)

<sup>&</sup>lt;sup>6</sup> Alzheimer's Association and Centers for Disease Control and Prevention. (2013) *The CDC Healthy Brain Initiative: Public Health Road Map for State and National Partnerships, 2013-2018.* 

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SLIDE 10:		
DEMENTIA		
TALKING POINTS:		

Next we turn to dementia.

FACULTY GUIDE

#### **SLIDE 11:**

#### Dementia<sup>7</sup>

- Decline in mental ability severe enough to interfere with daily life
- Not a specific disease
- Not normal aging
- Caused by damage to brain cells from disease or trauma
- Many dementias are progressive

#### **TALKING POINTS:**

Dementia is a general term for a **decline in mental ability** severe enough to interfere with daily life.

Dementia is not a specific disease. It's an overall term that describes a **wide range of symptoms** associated with a decline in memory or other thinking skills.

Dementia is **NOT normal aging**.

It is caused by **damage** to **brain cells** from disease or trauma (such as a brain injury or stroke). This damage interferes with the ability of brain cells to communicate with each other. When brain cells cannot communicate normally, thinking, behavior, and feelings can be affected.

Many dementias are progressive, meaning symptoms start out slowly and gradually get worse.

<sup>&</sup>lt;sup>7</sup> Alzheimer's Association. *What is Dementia?* Accessed June 8, 2015 from website: <a href="http://www.alz.org/what-is-dementia.asp#causes">http://www.alz.org/what-is-dementia.asp#causes</a>

#### **SLIDE 12:**

## Types of Dementia<sup>8</sup>

- Alzheimer's disease
- Vascular dementia
- Dementia with Lewy Bodies (DLB)
- Mixed dementia
- Parkinson's disease
- Frontotemporal dementia
- Creutzfeldt-Jakob disease
- Normal pressure hydrocephalus
- Huntington's disease
- Wernicke-Korsakoff Syndrome

#### **TALKING POINTS:**

#### (Provide descriptions as needed):

There are numerous types of dementia:

- Alzheimer's disease: description begins on slide #12
- Vascular dementia: description on slide #11
- Dementia with Lewy bodies (DLB): memory loss and thinking problems common in Alzheimer's disease; more likely to have initial or early symptoms such as sleep disturbances, well-formed visual hallucinations, and muscle rigidity or other parkinsonian movement features
- Mixed dementia: abnormalities linked to more than one type of dementia occur simultaneously in the brain; researchers increasingly believe a large number of dementia cases are of mixed pathology

National Institute on Aging. (2015) Alzheimer's Disease Fact Sheet.

Image source: clker.com

<sup>&</sup>lt;sup>8</sup> Alzheimer's Association. *Types of Dementia*. Accessed June 8, 2015 from website: http://www.alz.org/dementia/types-of-dementia.asp.

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- Parkinson's disease: brain changes begin in a region that plays a key role in movement; as changes gradually spread, they often begin to affect mental functions, including memory and the ability to pay attention, make sound judgments and plan the steps needed to complete a task
- Frontotemporal dementia: typical symptoms include changes in personality and behavior and difficulty with language; nerve cells in the front and side regions of the brain are especially affected
- Creutzfeldt-Jakob disease: rapidly fatal disorder that impairs memory and coordination and causes behavior changes; variant CJD ("mad cow disease") occurs in cattle and has been transmitted to people under certain circumstances
- Normal pressure hydrocephalus: symptoms include difficulty walking, memory loss, and inability to control urination; caused by the buildup of fluid in the brain
- Huntington's disease: progressive brain disorder caused by a single defective gene on chromosome 4; symptoms include abnormal involuntary movements, a severe decline in thinking and reasoning skills, irritability, depression, and other mood changes
- Wernicke-Korsakoff Syndrome: a chronic memory disorder caused by severe deficiency of thiamine (vitamin B-1); most common cause is alcohol misuse; memory problems may be strikingly severe while other thinking and social skills seem relatively unaffected

**Alzheimer's disease** and **vascular dementia** are the most **common** types of dementia.

#### **SLIDE 13:**

#### Vascular Dementia9

- 2<sup>nd</sup> most common cause of dementia.
- 20% 30% of cases
- Caused by conditions that block or reduce blood flow to the brain
- Symptoms may occur suddenly following strokes, or slowly as a result of cumulative damage

#### TALKING POINTS:

**Vascular dementia** is widely considered as the second most common cause of dementia after Alzheimer's disease, accounting for **20% to 30%** of cases.

Vascular dementia is a decline in thinking skills caused by conditions that block or reduce blood flow to the brain, depriving brain cells of vital oxygen and nutrients.

In vascular dementia, changes in thinking sometimes **occur suddenly** following strokes that block major brain blood vessels. Thinking problems may also begin as mild changes that worsen gradually as a result of multiple minor strokes or other conditions that affect smaller blood vessels, leading to cumulative damage.

Researchers increasingly believe that many people have mixed vascular dementia and Alzheimer's.

 $<sup>^{9}</sup>$  Alzheimer's Association. (2015) Vascular Dementia.

SLIDE 14:		
ALZHEIMER'S DISEASE		

#### **TALKING POINTS:**

The most common type of dementia is Alzheimer's disease. We will focus our attention on understanding more about the stages of Alzheimer's as well as risk factors, treatment and management of the disease.

#### **SLIDE 15:**

### Alzheimer's Disease: Overview<sup>10</sup>

- Most common type of dementia
- 60% 80% of cases
- Progressive symptoms gradually worsen over number of years

#### **TALKING POINTS:**

**Alzheimer's disease** is the most common type of dementia. It accounts for an estimated 60% to 80% of cases.

Alzheimer's disease is a progressive disease, in which dementia symptoms gradually worsen over a number of years.

In its mild (early) stages, people experience some memory loss, but with severe (late-stage) Alzheimer's disease, individuals lose the ability to carry on a conversation and respond to their environment. The degenerative nature of the disease means many in the severe stage have difficulty moving, often become bed-bound, and need around-the-clock care.

\*Note: The image on the slide shows a healthy brain (left side) as compared to a severe Alzheimer's brain (right side). The Alzheimer's brain is significantly smaller than the healthy brain.

http://www.alz.org/alzheimers disease what is alzheimers.asp

Image source: National Institute on Aging

<sup>&</sup>lt;sup>10</sup> Alzheimer's Association. *What is Alzheimer's?* Accessed June 8, 2015 from website:

#### **SLIDE 16:**

## Alzheimer's Disease: History<sup>11</sup>

- Identified in 1906 by Dr. Alois Alzheimer
- Examined brain of woman who died after mental illness
- Found abnormal clumps (plaques) and tangled fibers (tangles)

#### **TALKING POINTS:**

Alzheimer's disease was first **identified** in 1906 by Dr. Alois Alzheimer. He noticed certain changes in the brain tissue of a woman who had died after a mental illness that included symptoms of memory loss, language problems, and unpredictable behavior.

Dr. Alzheimer examined her brain after her death and found many **abnormal clumps** (now called amyloid plaques) and tangled bundles of fibers (now called neurofibrillary, or tau, tangles). These **plaques** and **tangles** in the brain are still considered some of the hallmarks of Alzheimer's disease, along with the loss of connections between **nerve cells** (neurons) in the brain.

<sup>&</sup>lt;sup>11</sup> National Institute on Aging. (2015) Alzheimer's Disease Fact Sheet.
Image source: National Library of Medicine, History of Medicine

#### **SLIDE 17:**

## Alzheimer's Disease: Physical Changes<sup>12</sup>

- Brain shrinks dramatically
  - o Nerve cell death
  - Tissue loss
- Plaques: abnormal clusters of protein fragments
- Tangles: twisted strands of another protein

#### **TALKING POINTS:**

Alzheimer's disease leads to **nerve cell death** and **tissue loss** throughout the brain. Over time, the brain **shrinks dramatically**, affecting nearly all its functions.

Scientists are not absolutely sure what causes cell death and tissue loss in the Alzheimer's brain, but **plaques** and **tangles** are prime suspects.

**Plaques**, abnormal clusters of protein fragments, build up between nerve cells in the brain. Plaques form when protein pieces called **beta-amyloid** clump together.

Dead and dying nerve cells contain **tangles**, which are made up of twisted strands of another protein.

Plaques and tangles tend to spread through the brain in a predictable pattern as Alzheimer's disease progresses.

\*Note: The image on the slide shows a microscopic illustration of Alzheimer's tissue with plaques and tangles.

**Video Supplement**: Inside the Brain: Unraveling the Mystery of Alzheimer Disease". National Institutes of Health, NIH Senior Health. (run time: 4 mins.)

http://nihseniorhealth.gov/alzheimersdisease/whatisalzheimersdisease/video/a2 na.html?intro=yes

Image source: National Institute on Aging

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<sup>&</sup>lt;sup>12</sup> Alzheimer's Association. *Brain Tour*. Accessed July 1, 2015 from website: <a href="http://www.alz.org/braintour/3">http://www.alz.org/braintour/3</a> main parts.asp

#### **SLIDE 18:**

### Alzheimer's Disease: Causes<sup>13</sup>

- Precise changes in brain largely unknown
- Probably develops as a result of complex interactions among:
  - o Age
  - Genetics
  - Environment
  - Lifestyle
  - Coexisting medical conditions

#### **TALKING POINTS:**

Although research has revealed a great deal about Alzheimer's disease, the precise **changes** that occur in the brain and trigger the development of the disease remain largely unknown.

Experts agree that in the vast majority of cases, Alzheimer's disease, like other common chronic conditions, probably develops as a result of complex interactions among multiple factors, including age, genetics, environment, lifestyle, and coexisting medical conditions.

It is likely that damage to the brain starts a decade or more before symptoms begin to appear.

<sup>&</sup>lt;sup>13</sup> Alzheimer's Association. Risk Factors. Accessed June 8, 2015 from website: <a href="http://www.alz.org/alzheimers">http://www.alz.org/alzheimers</a> disease causes risk factors.asp

### **SLIDE 19:**

## Younger-Onset Alzheimer's Disease<sup>14</sup>

- Affects people younger than 65
- Many are in their 40s and 50s
- 200,000 have younger onset (in U.S.)
- 4% of population with Alzheimer's

#### **TALKING POINTS:**

Alzheimer's disease is not just a disease of old age.

Younger-onset (also known as early-onset) Alzheimer's disease affects people younger than 65. Many people with early onset Alzheimer's disease are in their 40s and 50s.

In the U.S., it is estimated that approximately 200,000 people have younger onset Alzheimer's disease – up to 4% of the population with Alzheimer's disease.

http://www.alz.org/alzheimers disease early onset.asp

*Image source:* National Cancer Institute, NCI Visuals Online, Rhoda Baer (Photographer)

 $<sup>^{14}</sup>$  Alzheimer's Association. Younger/Early Onset Alzheimer's & Dementia. Accessed June 8, 2015 from website:

## **SLIDE 20:**

## **Discussion Question**

What are the characteristics of Alzheimer's disease?

**Ask:** What are the characteristics of Alzheimer's disease?

Open responses.

#### **SLIDE 21:**

## 10 Warning Signs of Alzheimer's 15

- 1. Memory loss that disrupts daily life
- 2. Challenges in planning or solving problems
- 3. Difficulty completing familiar tasks
- 4. Confusion with time or place
- 5. Trouble understanding visual images and spatial relationships

#### **TALKING POINTS:**

Alzheimer's disease affects people in different ways. Symptoms also change and become more severe as the disease progresses.

The most common symptom begins with **gradually worsening ability** to **remember new information**. As damage spreads, individuals experience other difficulties.

The following are **ten warning signs of Alzheimer's disease**:

#### 1. Memory loss that disrupts daily life

One of the most common signs of Alzheimer's disease, especially in the early stages, is forgetting recently learned information.

Others include: forgetting important dates or events; asking for the same information over and over; relying on memory aids (e.g., reminder notes or electronic devices) or family members for things they used to handle on their own.

#### 2. Challenges in planning or solving problems

Some people may experience changes in their ability to develop and follow a plan or work with numbers.

They may have trouble following a familiar recipe or keeping track of monthly bills.

 $<sup>^{15}</sup>$  Alzheimer's Association. (2009) Know the 10 Signs.

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They may have difficulty concentrating and take much longer to do things than they did before.

## **3.** Difficulty **completing familiar tasks** at home, at work or at leisure

People with Alzheimer's disease may have a hard time completing daily tasks. Sometimes, people may have trouble driving to a familiar location, managing a budget at work, or remembering the rules of a favorite game.

### 4. Confusion with time or place

People with Alzheimer's disease can lose track of dates, seasons, and the passage of time. They may have trouble understanding something if it is not happening immediately. Sometimes they may forget where they are or how they got there.

## Trouble understanding visual images and spatial relationships

For some people, having vision problems is a sign of Alzheimer's disease. They may have difficulty reading, judging distance and determining color or contrast. In terms of perception, they may pass a mirror and think someone else is in the room. They may not recognize their own reflection.

## **SLIDE 22:**

## Ten Warning Signs of Alzheimer's (continued)<sup>16</sup>

- **6.** New problems with words in speaking or writing
- **7.** Misplacing things and losing the ability to retrace steps
- 8. Decreased or poor judgment
- 9. Withdrawal from work or social activities
- 10. Changes in mood and personality

#### **TALKING POINTS:**

6. New problems with words in speaking or writing

People with Alzheimer's disease may have trouble following or joining a conversation. They may stop in the middle of a conversation and have no idea how to continue, or they may repeat themselves. They may struggle with vocabulary, have problems finding the right word, or call things by the wrong name (e.g., calling a watch a "hand clock").

7. Misplacing things and losing the ability to retrace steps

A person with Alzheimer's disease may put things in unusual places. They may lose things and be unable to go back over their steps to find them again. Sometimes, they may accuse others of stealing. This may occur more frequently over time.

8. Decreased or poor judgment

People with Alzheimer's disease may experience changes in judgment or decision-making. For example, they may use poor judgment when dealing with money, such as giving large amounts to telemarketers. They may pay less attention to grooming or keeping themselves clean.

9. Withdrawal from work or social activities

<sup>&</sup>lt;sup>16</sup> Alzheimer's Association. (2009) Know the 10 Signs.

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A person with Alzheimer's disease may start to remove themselves from hobbies, social activities, work projects or sports. They may have trouble keeping up with a favorite sports team or remembering how to complete a favorite hobby. They may also avoid being social because of the changes they have experienced.

## 10. Changes in mood and personality

The mood and personalities of people with Alzheimer's disease can change. They can become confused, suspicious, depressed, fearful or anxious. They may be easily upset at home, at work, with friends, or in places where they are out of their comfort zone.

#### **SLIDE 23:**

## Stages of Alzheimer's Disease<sup>17</sup>

- Average lifespan 4-8 years after diagnosis; as long as 20 years
- Progresses slowly in 3 stages:
  - Mild (early-stage)
  - Moderate (middle-stage)
  - Severe (late-stage)

#### **TALKING POINTS:**

On average, a person with Alzheimer's disease lives **four to eight years** after diagnosis, but can live as long as 20 years, depending on many factors (such as the progression of the disease, other co-occurring conditions, infections, and unintentional injuries).

The symptoms of Alzheimer's disease worsen over time, although the **rate** at which the disease progresses **varies**.

Alzheimer's disease typically progresses slowly in **three general stages** – mild (early-stage), moderate (middle-stage), and severe (late-stage).

\*Note: The image on the slide shows the progression of changes to the brain, from preclinical Alzheimer's (top), mild to moderate (middle), to severe (bottom).

http://www.alz.org/alzheimers disease stages of alzheimers.asp

Image source: National Institute on Aging

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<sup>&</sup>lt;sup>17</sup> Alzheimer's Association. *Stages of Alzheimer's*. Accessed June 8, 2015 from website:

## **SLIDE 24:**

## Mild Alzheimer's (Early-Stage)<sup>18</sup>

- Able to function independently
- Common difficulties:
  - Forgetting familiar words
  - Losing everyday objects
  - Trouble remembering names
  - Greater difficulty performing tasks
  - o Forgetting material just read
  - Increasing trouble with planning, organizing

#### **TALKING POINTS:**

In the mild stages of Alzheimer's disease, a person may function **independently**. He or she may still **drive**, **work** and be part of **social activities**.

Despite this, the person may feel as if he or she is having memory lapses, such as forgetting familiar words or the location of everyday objects.

Other common difficulties in the mild stage of Alzheimer's disease include:

- Trouble remembering names when introduced to new people
- Having greater difficulty performing tasks in social or work settings
- Forgetting material that one has just read
- Increasing trouble with planning or organizing

http://www.alz.org/alzheimers disease stages of alzheimers.asp

<sup>&</sup>lt;sup>18</sup> Alzheimer's Association. *Stages of Alzheimer's*. Accessed June 8, 2015 from website:

#### **SLIDE 25:**

## Moderate Alzheimer's (Middle-Stage)<sup>19</sup>

- Requires increasing care
- Symptoms include:
  - Forgetfulness of personal history
  - Confusion about place or time
  - Need for help with bathing, toileting, dressing
  - Changes in sleep patterns
  - Increased risk of wandering
  - o Personality and behavioral changes

#### **TALKING POINTS:**

As the disease progresses, a person with Alzheimer's disease will require a **greater level of care**.

In the moderate stage, damage to nerve cells in the brain can make it difficult to express thoughts and perform routine tasks.

During this stage, symptoms will be noticeable to others and may include:

- Forgetfulness of events or about one's own personal history
- Confusion about where they are or what day it is
- The need for help choosing proper clothing for the season or the occasion
- Trouble controlling bladder and bowels in some individuals
- Changes in sleep patterns, such as sleeping during the day and becoming restless at night
- An increased risk of wandering and becoming lost

http://www.alz.org/alzheimers disease stages of alzheimers.asp

<sup>&</sup>lt;sup>19</sup> Alzheimer's Association. *Stages of Alzheimer's*. Accessed June 8, 2015 from website:

### Module 2: Alzheimer's and Other Dementias – The Basics

 Personality and behavioral changes, including suspiciousness and delusions or compulsive, repetitive behavior like hand-wringing or tissue shredding

## **SLIDE 26:**

## Severe Alzheimer's (Late-Stage)<sup>20</sup>

- Typically longest stage
- Requires full-time care
- Loss of awareness of recent experiences and surroundings
- Changes in physical abilities (walking, sitting, swallowing)
- Vulnerable to infections

#### TALKING POINTS:

The severe stage of Alzheimer's disease is typically the **longest stage** and can last for many years. In the severe stage of Alzheimer's disease, individuals lose the ability to respond to their environment, to carry on a conversation, and, eventually, to control movement. They may still say words or phrases, but **communicating** becomes difficult.

As memory and **cognitive skills** continue to worsen, **personality** changes may take place, and individuals need **extensive help** with daily activities. At this stage, individuals may:

- Require full-time, around-the-clock assistance with daily personal care
- Lose awareness of recent experiences as well as of their surroundings
- Experience changes in **physical abilities**, including the ability to walk, sit, and eventually, swallow
- Become vulnerable to infections, especially pneumonia

http://www.alz.org/alzheimers disease stages of alzheimers.asp

*Image source:* Copyrighted image; used with permission from the Alzheimer's Association

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<sup>&</sup>lt;sup>20</sup> Alzheimer's Association. *Stages of Alzheimer's*. Accessed June 8, 2015

## Module 2: Alzheimer's and Other Dementias – The Basics

SLIDE 27:		
RISK FACTORS		
TALKING POINTS:		

Next we turn to risk factors for Alzheimer's disease.

## **SLIDE 28:**

Risk Factors: Age<sup>21,22</sup>

- #1 risk factor is advancing age
- Doubles every 5 years after age 65
- 1 in 3 people age ≥85

#### **TALKING POINTS:**

Currently, researchers don't fully understand what causes Alzheimer's disease in most people. As described earlier, in most cases it is likely a combination of **genetic**, **environmental**, and **lifestyle** factors that take place over a long period of time.

A number of risk factors have been identified that contribute to the development of Alzheimer's disease. Other risk factors show evidence of decreased risk pending further research.

The greatest risk factor for Alzheimer's disease is **advancing age**. Most individuals with the disease are age 65 or older. However, Alzheimer's and dementia are not normal parts of aging.

The risk of developing Alzheimer's disease increases with age – it approximately doubles every five years after age 65. In persons age 85 or older, about one in three have Alzheimer's disease.

*Image source:* Copyrighted image; used with permission from the Alzheimer's Association

Alzheimer's Association. Risk Factors. Accessed June 8, 2015 from website: <a href="http://www.alz.org/alzheimers disease causes risk factors.asp">http://www.alz.org/alzheimers disease causes risk factors.asp</a>
 Alzheimer's Association, 2015 Alzheimer's Disease Facts and Figures, March 2015

## **SLIDE 29:**

## Risk Factors: Family History, Education <sup>23</sup>

- Family history
  - Hereditary (genetics)
    - Risk genes
    - Deterministic genes
  - Environmental factors
- Years of formal education

#### **TALKING POINTS:**

In addition to advancing age, another strong risk factor is **family history**. People who have an immediate family member – a parent, brother, sister, or child – with Alzheimer's disease are more likely to develop the disease. This risk increases if more than one family member has the disease.

When diseases tend to run in families, either **hereditary** (genetics) or environmental factors, or both, may play a role.

Scientists have identified numerous **hereditary genes** that either increase the likelihood or guarantee that people with the gene will develop Alzheimer's disease.

- Risk genes: increase the likelihood of developing a disease, but do not guarantee it will happen.
   Scientists have identified several risk genes, including APOE-e4, tied to Alzheimer's disease.
- Deterministic genes: directly cause a disease, guaranteeing that anyone who inherits them will develop the disorder. Scientists have discovered variations that directly cause Alzheimer's disease in the genes of three proteins. This is very rare, representing perhaps 1% of Alzheimer's cases. Onset for Alzheimer's disease related to these genes tends to

*Image source:* Copyrighted image; used with permission from the Alzheimer's Association

<sup>&</sup>lt;sup>23</sup> Alzheimer's Association. *Risk Factors*. Accessed June 8, 2015 from website: <a href="http://www.alz.org/alzheimers">http://www.alz.org/alzheimers</a> disease causes risk factors.asp

#### Module 2: Alzheimer's and Other Dementias - The Basics

occur at a very young age, including people in their 30s.

Researchers are trying to determine the link between dementias and possible environmental factors such as exposure to pesticides, food additives, air pollution and other problematic chemical compounds.

Several studies have demonstrated that fewer years of formal education and lower levels of cognitive engagement are indicators of risk for dementia. People who have more years of formal education have lower rates of Alzheimer's and other dementias than those with less education. Additional studies suggest that remaining socially and mentally active throughout life may support brain health and possibly reduce the risk of Alzheimer's and other dementias.

Some researchers have proposed a "cognitive reserve" hypothesis, in which ongoing mental activity and stimulation, such as through education, occupation, leisure activity, mental and physical activity, may help protect the brain against damage and decline.

## **SLIDE 30:**

Risk Factors: Race & Ethnicity<sup>24</sup>

• African-Americans: 2 times greater risk

Hispanics: 1.5 times greater risk

Cardiovascular risk factors more common

• Lower levels of education, socioeconomic status

#### **TALKING POINTS:**

Race and ethnicity may also contribute to increased risk of developing Alzheimer's and other dementias. In the U.S., older African-Americans are about two times more likely than older whites to have Alzheimer's disease. First-degree relatives of African-Americans with Alzheimer's disease have a 43% chance of developing dementia.

Older **Hispanics** are about **one and one-half times more likely** than older whites to have Alzheimer's disease. Variations in health, lifestyle and socioeconomic circumstances across racial groups likely account for most of the differences in risk of Alzheimer's and other dementias by race. For example, African-American and Hispanic communities have higher incidence of certain Alzheimer's risk factors:

- Conditions such as high blood pressure and diabetes which are risk factors for Alzheimer's disease, are more common in African-Americans and Hispanic populations than in whites.
- Lower levels of education and other socioeconomic characteristics (such as lower income, access to quality care) among older racial and ethnic minorities may also contribute to increased risk.

Some studies suggest that differences based on race and ethnicity do not persist in rigorous analyses that account for such risk factors.

*Image source:* Copyrighted image; used with permission from the Alzheimer's Association

<sup>&</sup>lt;sup>24</sup> Alzheimer's Association. *2016 Alzheimer's Disease Facts and Figures*.

## **SLIDE 31:**

Risk Factors: Women<sup>25,26</sup>

- 2/3 of affected population
- 16% of women age ≥ 71 (11% of men)
- After age 65, have more than 1 in 6 chance (1 in 11 for men)
- Age ≥ 60, twice as likely to develop Alzheimer's than breast cancer

#### **TALKING POINTS:**

- Almost 2/3 of U.S. adults with Alzheimer's disease are women.
- Among those aged 71 and older, 16% of women have Alzheimer's and other dementias, compared with 11% of men.
- At age 65, women without Alzheimer's disease have more than a one in six chance of developing Alzheimer's disease during the remainder of their lives, compared with a one in 11 chance for men.
- Women in their 60s are about twice as likely to develop Alzheimer's disease over the rest of their lives as they are to develop breast cancer.

This may be primarily explained by the fact that women live longer, on average, than men.

However, researchers are increasingly questioning whether there may be other reasons for the difference in the number of women and men who develop the disease.

*Image source:* National Cancer Institute, NCI Visuals Online, Daniel Sone (Photographer)

<sup>&</sup>lt;sup>25</sup> Alzheimer's Association, AAIC Press Release, July 21, 2015

<sup>&</sup>lt;sup>26</sup> Alzheimer's Association, *Public Health E-News*, July 22, 2015

## **SLIDE 32:**

## Modifiable Risk Factors: Head Trauma<sup>27</sup>

- Moderate and severe traumatic brain injury
  - Moderate injury: 2.3 times greater risk
  - Severe injury: 4.5 times greater risk
- Risk remains for years after injury

#### **TALKING POINTS:**

There are some risk factors that may be changed or prevented to help reduce the risk of developing Alzheimer's disease.

Research has linked **moderate and severe traumatic brain injury to** a greater risk of developing Alzheimer's or another type of dementia years after the original head injury.

One of the key studies showing an increased risk found that older adults with a history of **moderate traumatic brain injury** (unconsciousness lasting more than 30 minutes) had a 2.3 times greater risk of developing Alzheimer's disease than seniors with no history of head injury.

Those with a history of **severe traumatic brain injury** (unconsciousness lasting more than 24 hours) had a 4.5 times greater risk. Also, people with repeated head injuries (such as boxers, football players, and combat veterans) are at an even higher risk of developing dementia.

Image source: clker.com

 $<sup>^{27}</sup>$  Alzheimer's Association. (2015) *Traumatic Brain Injury*.

## **SLIDE 33:**

## Modifiable Risk Factors: Lifestyle<sup>28,29</sup>

- Increases risk
  - Current smoking
  - Midlife obesity
- Decreases risk
  - Physical activity
  - o Heart-healthy diets: DASH, Mediterranean diet
  - Mental and social activity

#### **TALKING POINTS:**

Certain **lifestyle factors** may help to protect against developing Alzheimer's and other dementias.

There is fairly strong evidence that **current smoking** increases the risk of cognitive decline and possibly also dementia, and that quitting smoking may reduce the associated risk to levels comparable to those who have never smoked.

**Diet** and **physical activity** may help to prevent against **obesity**; midlife obesity has been shown to increase risk for Alzheimer's and other dementias.

**Exercise** may also directly benefit brain cells by increasing blood and oxygen flow in the brain.

Current evidence also suggests that eating a **heart-healthy diet** may also help protect the brain against cognitive decline.

Two diets that have been studied and may be beneficial are the **DASH** (**Dietary Approaches to Stop Hypertension**) diet and the **Mediterranean diet**.

<sup>&</sup>lt;sup>28</sup> Alzheimer's Association. (2014) *Alzheimer's and Public Health Spotlight: Heart Health and Brain Health*.

<sup>&</sup>lt;sup>29</sup> Alzheimer's Association. *Prevention and Risk of Alzheimer's & Dementia*. Accessed July 16, 2015 from website: http://www.alz.org/research/science/alzheimers prevention and risk.asp

## Module 2: Alzheimer's and Other Dementias – The Basics

- The DASH diet emphasizes vegetables, fruits, and fatfree or low-fat dairy products; includes whole grains, fish, poultry, beans, seeds, nuts, and vegetable oils; and limits sodium, sweets, sugary beverages, and red meats.
- The Mediterranean diet includes relatively little red meat and emphasizes whole grains, fruits and vegetables, fish and shellfish, and nuts, olive oil and other healthy fats.

Some studies have also indicated that staying **cognitively** and **socially active** may help reduce the risk of cognitive decline. This involves mentally stimulating activities and social connections.

## **SLIDE 34:**

## Modifiable Risk Factors: Cardiovascular<sup>30</sup>

- Heart-head connection
- Cardiovascular risk factors:
  - o High blood pressure in midlife
  - Heart disease
  - Stroke
  - Diabetes

#### **TALKING POINTS:**

Growing evidence suggests that the health of the brain is closely linked to the overall health of the **heart** and **blood vessels**.

The brain is nourished by one of the body's richest networks of blood vessels. With every beat, the **heart pumps about 20% to 25% of the blood to the head,** where brain cells use at least 20% of the food and oxygen carried by the blood in order to function normally.

As a result, many factors that damage the heart or blood vessels may also damage the brain – and may increase the risk for developing Alzheimer's and other dementias.

Several conditions known to increase the risk of **cardiovascular disease** – including high blood pressure, heart disease, stroke, and diabetes– appear to increase the risk of developing Alzheimer's disease.

Some autopsy studies show that as many as **80% of individuals** with Alzheimer's disease also have cardiovascular disease.

http://www.alz.org/research/science/alzheimers prevention and risk.asp

Image source: clker.com

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 $<sup>^{30}</sup>$  Alzheimer's Association. Prevention and Risk of Alzheimer's & Dementia. Accessed July 16, 2015 from website:

## **SLIDE 35:**

## TREATMENT & MANAGEMENT

## **TALKING POINTS:**

Next we will discuss how Alzheimer's disease is diagnosed, treated, and managed.

## **SLIDE 36:**

## Diagnosing Alzheimer's Disease<sup>31</sup>

- No single test
- Medical evaluation
  - Medical history
  - Mental status testing
  - o Information from family and friends
  - Physical and neurological exams
  - Rule out other causes

#### **TALKING POINTS:**

Physicians can almost always determine if a person has **dementia**; however it can be difficult to identify the exact cause.

Establishing a diagnosis for **Alzheimer's disease** can be more challenging. There is no single test that can show whether a person has Alzheimer's disease.

A careful medical evaluation is required, which includes:

- A thorough medical history
- Mental status testing
- Information from family and friends
- A physical and neurological exam
- Tests (such as blood tests and brain imaging) to rule out other causes of dementia-like symptoms.

Image source: National Cancer Institute, NCI Visuals Online

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<sup>&</sup>lt;sup>31</sup> Alzheimer's Association. *Diagnosis of Alzheimer's Disease and Dementia*. Accessed June 8, 2015 from website: http://www.alz.org/alzheimers\_disease\_diagnosis.asp

## **SLIDE 37:**

## Treating & Managing Alzheimer's<sup>32</sup>

- No cure
- Drug and non-drug treatments
- Goals of treatment
  - o Maintain quality of life
  - Maximize functioning in daily activities
  - Foster safe environment
  - o Promote social engagement

### **TALKING POINTS:**

Currently, there is no cure for Alzheimer's disease and no treatment that slows the progression of the disease. Drug and non-drug treatments may help with both cognitive and behavioral *symptoms*, but don't affect the underlying disease.

**Medications** are used to treat symptoms and are more effective if administered after early diagnosis.

The chief goals of treatment are to:

- Maintain quality of life
- Maximize function in daily activities
- Enhance cognition, mood and behavior
- Foster a safe environment
- Promote social engagement, as appropriate

Image source: clker.com

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<sup>&</sup>lt;sup>32</sup> Alzheimer's Association. *Health Care Professionals and Alzheimer's*. Accessed June 8, 2015 from website: <a href="http://www.alz.org/health-care-professionals/medical-management-patient-care.asp">http://www.alz.org/health-care-professionals/medical-management-patient-care.asp</a>

## **SLIDE 38:**

## Alzheimer's: Co-Morbidities<sup>33</sup>

- Additional chronic conditions (e.g., heart disease, diabetes, depression)
- Difficult to manage
- Higher rates of hospitalizations and costs
  - o 3 times as many hospital stays
  - 3 times average Medicare costs
- Preventable hospitalizations

#### **TALKING POINTS:**

Treating people with Alzheimer's often requires the management of **co-morbidities**. Co-morbidities refer to additional chronic conditions – such as heart disease, diabetes, depression, and arthritis – that are present in combination with a primary disease. People with Alzheimer's and dementia are **more likely** to have co-morbidities than other older people without dementia.

The cognitive problems associated with Alzheimer's disease and dementia can lead to **poor management** of comorbidities. On average, people with dementia have **three times** as many **hospital stays** and have **three times** the average **Medicare costs** of other older people.

Most of the hospitalizations are not for Alzheimer's disease itself, but for these other conditions that are often complicated by, or result from, Alzheimer's disease. Many of these hospitalizations are preventable (or potentially avoidable) with better quality care and management of comorbidities.

*Image source:* Copyrighted image; used with permission from the Alzheimer's Association

<sup>&</sup>lt;sup>33</sup> Alzheimer's Association. (2013) *Combating Alzheimer's Disease: A Public Health Agenda.* 

SLIDE 39:			

## **UNIQUE ASPECTS**

## **TALKING POINTS:**

There are various unique aspects and hardships that may accompany Alzheimer's and other dementias.

## **SLIDE 40:**

## Alzheimer's: Unique Aspects<sup>34</sup>

- Financial hardship
  - May lose income and savings
  - o Increased reliance on public programs
- Stigma
- Vulnerability to abuse

#### **TALKING POINTS:**

People with younger-onset dementia may **lose income and savings** when they become unable to work. Those with dementia at any age may need to pay for additional services, especially as the disease progresses.

As the need for care intensifies, many people with Alzheimer's and dementia may live in nursing homes for long periods of time. The financial burden of this care can result in turning to **Medicaid** and other **public programs** to help pay for their services and support.

People with dementia report being **afraid** of the reactions of others and a **lower perceived status** within society because of the diagnosis. The stigma associated with dementia may contribute to **social exclusion**, a reluctance to seek **help** or even a diagnosis, a sense of **shame** and **inadequacy**, and **low self-esteem**.

People with Alzheimer's and other dementias tend to be especially **vulnerable to abuse** because the disease may prevent them from reporting the abuse or recognizing it. Abuse can occur anywhere, including at home and in care settings.

Abuse can take many forms:

• Physical: physical pain or injury

<sup>&</sup>lt;sup>34</sup> Alzheimer's Association. *Abuse*. Accessed July 16, 2015 from website: <a href="https://www.alz.org/care/alzheimers-dementia-elder-abuse.asp">https://www.alz.org/care/alzheimers-dementia-elder-abuse.asp</a>

## Module 2: Alzheimer's and Other Dementias – The Basics

- **Emotional**: verbal assaults, threats of abuse, harassment and intimidation
- **Neglect**: failure to provide necessities, including food, clothing, shelter, medical care or a safe environment
- **Financial**: the misuse or withholding of the person's financial resources (money, property) to his or her disadvantage or the advantage of someone else

SLIDE 41:		
CAREGIVERS		

## **TALKING POINTS:**

Most people with Alzheimer's disease have a primary caregiver – often a family member – who is crucial to ensuring appropriate care. As the person with Alzheimer's declines, the primary caregiver(s) often takes on an increasing role in advocating for and attending to all aspects of the person's health and well-being as well as all their financial affairs.

## **SLIDE 42:**

## Alzheimer's: Caregivers<sup>35</sup>

- Responsibilities:
  - Dressing, bathing, toileting, feeding
  - Shopping, meal preparation, transportation
  - Medication
  - o Financial management
  - Emotional support
- Increasing levels of care
- Results in complete dependence

#### **TALKING POINTS:**

The term **caregiver** is used to describe a person who provides a level of care and support for another that exceeds typical responsibilities of daily life.

Caregiving responsibilities, especially in the moderate and severe stages, often include:

- Helping with dressing, bathing, toileting, and feeding
- Shopping, meal preparation, transportation, medication management, and financial management
- Providing emotional support

People with Alzheimer's require increasing levels of caregiving as the disease progresses; more severe stages may require constant supervision and result in complete dependence on caregivers (paid or unpaid).

*Image source:* Copyrighted image; used with permission from the Alzheimer's Association

<sup>&</sup>lt;sup>35</sup> Alzheimer's Association. (2015) *Alzheimer's Disease Caregivers*.

## **SLIDE 43:**

## Caregivers: Challenges<sup>36</sup>

- Physical, financial, psychological challenges
  - \$10.2 billion additional annual health care costs (2015)
  - 60% rate emotional stress as high or very high
  - o 40% report depression

#### **TALKING POINTS:**

Being a caregiver for someone with Alzheimer's disease can take a significant **physical** and **emotional** toll.

- Due to the physical and emotional toll of caring for someone with Alzheimer's or other dementias, these caregivers had \$10.2 billion in additional health care costs in 2014.
- Nearly 60% of Alzheimer's and dementia caregivers rate the emotional stress of caregiving as high or very high.
- About 40% of Alzheimer's and dementia caregivers suffer from depression.

*Image source:* National Cancer Institute, NCI Visuals Online, Daniel Sone (Photographer)

<sup>&</sup>lt;sup>36</sup> Alzheimer's Association. 2016 Alzheimer's Disease Facts and Figures.

## **SLIDE 44:**

## **Conclusion: Key Points**

- Likely develops as a result of multiple factors
- Symptoms worsen over time, average lifespan
   4-8 years (up to 20)
- Risk factors include: age, family history, head trauma, education, cardiovascular conditions
- African-Americans, Hispanics, women more likely to develop
- Risk reduction may include: physical activity, diet mental stimulation, social connections

#### **TALKING POINTS:**

In conclusion, a review of key points from Module 2:

- Experts agree that in the vast majority of cases,
   Alzheimer's disease, like other common chronic
   conditions, probably develops as a result of complex
   interactions among multiple factors, including age,
   genetics, environment, lifestyle, and coexisting
   medical conditions.
- The symptoms of Alzheimer's disease worsen over time, although the rate at which the disease progresses varies.
- On average, a person with Alzheimer's disease lives four to eight years after diagnosis, but can live as long as 20 years, depending on other factors.
- Risk factors for Alzheimer's disease include:
  - Age
  - Years of formal education
  - o Family history
  - Head trauma
  - Education
  - Lifestyle (current smoking, physical activity, diet, mental and social activity)

## Module 2: Alzheimer's and Other Dementias – The Basics

- Cardiovascular conditions (including high blood pressure, heart disease, stroke, and diabetes)
- African-Americans, Hispanics, and women are more likely to develop Alzheimer's disease.
  - In the U.S., older African-Americans are about two times more likely than older whites to have Alzheimer's disease. First-degree relatives of African-Americans with Alzheimer's disease have a 43% chance of developing dementia.
  - Older Hispanics are about one and one-half times more likely than older whites to have Alzheimer's disease.
  - Almost 2/3 of U.S. adults with Alzheimer's disease are women.

## **SLIDE 45:**

### **Role of Public Health**

- 3 key public health intervention tools:
  - Surveillance/monitoring
  - Primary prevention (risk reduction)
  - Early detection and diagnosis

## **TALKING POINTS: (see module 3 for more information)**

Public health plays an important part in addressing Alzheimer's. Three key public health intervention tools that can reduce the burden of Alzheimer's disease:

- **Surveillance/monitoring** that allows public health to compile data and use it to:
  - Develop interventions
  - Inform public policy
  - o Guide research
  - Educate populations
- **Promoting primary prevention** can be used to promote **risk reduction** and **promote cognitive health**.
- Public health may play an important role increasing early detection and diagnosis of Alzheimer's disease

*Image source:* Copyrighted image; used with permission from the Alzheimer's Association

## **SLIDE 46:**

# Dementia Capable Systems and Dementia Friendly Communities

- Dementia capable systems
  - Public health research and translation
  - Support services
  - Workforce training
- Dementia friendly communities

## **TALKING POINTS: (see module 4 for more information)**

At a larger level, states and communities can become dementia capable in accommodating the needs of a population with Alzheimer's and other dementias.

A dementia capable system is a system or infrastructure that works to meet the needs of a people with dementia and their caregivers through providing education, support and services.

Public health can contribute to a **dementia capable system** through:

- Public health research and translation
- Ensuring access to support services for people with dementia and their caregivers
- Workforce training and education
- Supporting the creation of dementia friendly communities which describes communities that have taken steps to make their community safe for and accessible to people with Alzheimer's and other dementias as well as support and empower people with Alzheimer's and dementia to continue living highquality lives with as much independence as possible.

*Image source:* Copyrighted image; used with permission from the Alzheimer's Association

## **SLIDE 47:**

## **For More Information**

For more information, please visit the Alzheimer's Association website at: <a href="http://www.alz.org">http://www.alz.org</a>

## **TALKING POINTS:**

For more information on the topics covered in this presentation, please go to the Alzheimer's Association website at <a href="http://www.alz.org">http://www.alz.org</a>. There you can find resources, latest research and information.

# A PUBLIC HEALTH APPROACH TO ALZHEIMER'S AND OTHER DEMENTIAS

ALZHEIMER'S & OTHER DEMENTIAS – THE BASICS







Emory Centers for Training and Technical Assistance

# **LEARNING OBJECTIVES**

- Define cognitive health
- Define and differentiate between dementia and Alzheimer's
- List at least 5 common symptoms of Alzheimer's
- Describe the changes that occur during the course of Alzheimer's
- Identify at least 3 risk factors associated with Alzheimer's
- Describe the role of caregivers

2

## **COMPETENCIES**

### Association for Gerontology in Higher Education (AGHE):

- 1.2.1 Distinguish normal biological aging changes from pathology including genetic factors.
- 1.3.3 Demonstrate knowledge of signs, symptoms, and impact of common cognitive and mental health problems in late life (e.g., dementia, depression, grief, anxiety).
- 1.2.4 Recognize common late-life syndromes and diseases and their related biopsycho-social risk and protective factors.

#### Association of Schools and Programs of Public Health (ASPPH):

Domain 1: Describe risk factors and modes of transmission for infectious and chronic diseases and how these diseases affect both personal and population health.

3

## COMPETENCIES CONT.

#### National Association of Chronic Disease Directors (NACDD):

Domain 7: Discuss the underlying causes and management of chronic diseases, including behavioral, medical, genetic, environmental and social factors.

Domain 7: Articulate key chronic disease issues.

Domain 7: Describe socioeconomic and behavioral determinants of health disparities.

# National Commission for Health Education Credentialing, Inc. (NCHEC):

7.1.1 Identify current and emerging issues that may influence health and health education

4

# DISCUSSION QUESTION

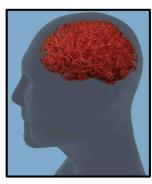


What is cognitive health?

5

# **COGNITIVE HEALTH**

- Cognition: the ability to think, learn, and remember
- Cognitive health continuum: "optimal functioning" to severe disability
- Linked to brain health



<sup>1</sup> Centers for Disease Control and Prevention, Division of Healthy Aging. What is a Healthy Brain? New Research Explores Perceptions of Cognitive Health Among Diverse Older Adults.

# **COGNITIVE AGING**

- The brain changes as it ages
- Increase in wisdom and expertise
- Speed of processing, making decisions, remembering may decline
- Normal part of aging



<sup>2</sup> Institute of Medicine. (2015) Cognitive Aging: Progress in Understanding and Opportunities for Action. <sup>3</sup> National Institute on Aging. (2013) Understanding Memory Loss: What To Do When you Have Trouble Remembering.

# MILD COGNITIVE IMPAIRMENT (MCI)

- Difficulty with cognitive processes
- Not severe enough to interfere with daily life
- Increased risk of Alzheimer's or dementia
- May be caused by external factors (vitamin B12 deficiency, depression)

<sup>&</sup>lt;sup>4</sup>Alzheimer's Association. (2012) *Mild Cognitive Impairment*.
<sup>5</sup> National Institute on Aging, About Alzheimer's Disease: Mild Cognitive Impairment. Accessed June 10, 2015 from website: <a href="https://www.nia.nih.gov/alzheimers/topics/mild-cognitive-impairment">https://www.nia.nih.gov/alzheimers/topics/mild-cognitive-impairment</a>.

# COGNITIVE IMPAIRMENT

- Difficulty with cognitive processes that affect everyday life
- Spans wide range of functioning
- Can occur as a result of Alzheimer's, dementia, stroke, traumatic brain injury



<sup>6</sup> Alzheimer's Association and Centers for Disease Control and Prevention. (2013) The CDC Healthy Brain Initiative: Public Health Road Map for State and National Partnerships, 2013-2018.

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## **DEMENTIA**

ALZHEIMER'S AND OTHER DEMENTIAS – THE BASICS

# **DEMENTIA**

- Decline in mental ability severe enough to interfere with daily life
- Not a specific disease
- Not normal aging
- Caused by damage to brain cells from disease or trauma
- Many dementias are progressive

<sup>7</sup> Alzheimer's Association. What is Dementia? Accessed June 8, 2015 from website: http://www.alz.org/what-is-dementia.asp#causes

# TYPES OF DEMENTIA

- Alzheimer's disease
- Vascular dementia
- Dementia with Lewy Bodies (DLB)
- Mixed dementia
- Parkinson's disease
- Frontotemporal dementia
- Creutzfeldt-Jakob disease
- Normal pressure hydrocephalus
- Huntington's disease
- Wernicke-Korsakoff Syndrome



<sup>8</sup> Alzheimer's Association. Types of Dementia. Accessed June 8, 2015 from website: <a href="http://www.alz.org/dementia/types-of-dementia.asp.">http://www.alz.org/dementia/types-of-dementia.asp.</a> National Institute on Aging. (2015) Alzheimer's Disease Fact Sheet.

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# VASCULAR DEMENTIA

- 2<sup>nd</sup> most common cause of dementia
- **20% 30% of cases**
- Caused by conditions that block or reduce blood flow to the brain
- Symptoms may occur suddenly following strokes or slowly as a result of cumulative damage

<sup>9</sup> Alzheimer's Association. (2015) Vascular Dementia.

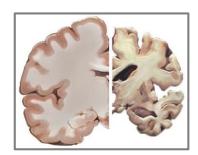
13

# ALZHEIMER'S DISEASE ALZHEIMER'S AND OTHER DEMENTIAS – THE BASICS

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## ALZHEIMER'S DISEASE: OVERVIEW

- Most common type of dementia
- 60% 80% of cases
- Progressive symptoms gradually worsen over number of years



<sup>10</sup> Alzheimer's Association. What is Alzheimer's? Accessed June 8, 2015 from website: <a href="http://www.alz.org/alzheimers\_disease\_what\_is\_alzheimers.asp">http://www.alz.org/alzheimers\_disease\_what\_is\_alzheimers.asp</a>

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# ALZHEIMER'S DISEASE: HISTORY

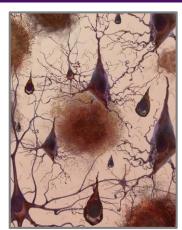
- Identified in 1906 by Dr. Alois Alzheimer
- Examined brain of woman who died after mental illness
- Found abnormal clumps (plaques) and tangled fibers (tangles)



11 National Institute on Aging. (2015) Alzheimer's Disease Fact Sheet.

# ALZHEIMER'S DISEASE: PHYSICAL CHANGES

- Brain shrinks dramatically
  - Nerve cell death
  - Tissue loss
- Plaques: abnormal clusters of protein fragments
- Tangles: twisted strands of another protein



<sup>12</sup> Alzheimer's Association. Brain Tour. Accessed July 1, 2015 from website: http://www.alz.org/braintour/3\_main\_parts.asp

## **ALZHEIMER'S DISEASE: CAUSES**

- Precise changes in brain largely unknown
- Probably develops as a result of complex interactions among:
  - Age
  - Genetics
  - Environment
  - Lifestyle
  - Coexisting medical conditions

<sup>13</sup> Alzheimer's Association. Risk Factors. Accessed June 8, 2015 from website: http://www.alz.org/alzheimers\_disease\_causes\_risk\_factors.asp 18

# YOUNGER-ONSET ALZHEIMER'S DISEASE

- Affects people younger than 65
- Many are in their 40s and 50s
- 200,000 have younger onset (in U.S.)
- 4% of population with Alzheimer's



14 Alzheimer's Association. Younger/Early Onset Alzheimer's & Dementia. Accessed June 8, 2015 from website: http://www.alz.org/alzheimers\_disease\_early\_onset.asp

# **DISCUSSION QUESTION**



What are the characteristics of Alzheimer's disease?

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## **10 WARNING SIGNS OF ALZHEIMER'S**

- 1. Memory loss that disrupts daily life
- 2. Challenges in planning or solving problems
- 3. Difficulty completing familiar tasks
- 4. Confusion with time or place
- 5. Trouble understanding visual images and spatial relationships

15 Alzheimer's Association. (2009) Know the 10 Signs.

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# 10 WARNING SIGNS OF ALZHEIMER'S (CONTINUED)

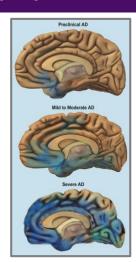
- 6. New problems with words in speaking or writing
- 7. Misplacing things and losing the ability to retrace steps
- 8. Decreased or poor judgment
- 9. Withdrawal from work or social activities
- 10. Changes in mood and personality

<sup>16</sup> Alzheimer's Association. (2009) Know the 10 Signs.

## STAGES OF ALZHEIMER'S DISEASE

- Average lifespan 4-8 years after diagnosis; as long as 20 years
- Progresses slowly in 3 stages:
  - Mild (early-stage)
  - Moderate (middle-stage)
  - Severe (late-stage)

<sup>17</sup> Alzheimer's Association. Stages of Alzheimer's. Accessed June 8, 2015 from website: <a href="http://www.alz.org/alzheimers\_disease\_stages">http://www.alz.org/alzheimers\_disease\_stages\_of\_alzheimers.asp</a>



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# MILD ALZHEIMER'S (EARLY-STAGE)

- Able to function independently
- Common difficulties:
  - o Forgetting familiar words
  - Losing everyday objects
  - Trouble remembering names
  - Greater difficulty performing tasks
  - o Forgetting material just read
  - o Increasing trouble with planning, organizing

<sup>18</sup> Alzheimer's Association. Stages of Alzheimer's. Accessed June 8, 2015 from website: http://www.alz.org/alzheimers\_disease\_stages\_of\_alzheimers.asp

## MODERATE ALZHEIMER'S (MIDDLE-STAGE)

- Requires increasing care
- Symptoms include:
  - Forgetfulness of personal history
  - Confusion about place or time
  - o Need for help with bathing, toileting, dressing
  - o Changes in sleep patterns
  - o Increased risk of wandering
  - Personality and behavioral changes

<sup>19</sup> Alzheimer's Association. Stages of Alzheimer's. Accessed June 8, 2015 from website: http://www.alz.org/alzheimers\_disease\_stages\_of\_alzheimers.asp .

## SEVERE ALZHEIMER'S (LATE-STAGE)

- Typically longest stage
- Requires full-time care
- Loss of awareness of recent experiences and surroundings
- Changes in physical abilities (walking, sitting, swallowing)
- Vulnerable to infections



<sup>20</sup> Alzheimer's Association. Stages of Alzheimer's. Accessed June 8, 2015 from website: http://www.alz.org/alzheimers\_disease\_stages\_of\_alzheimers.asp

## **RISK FACTORS**

ALZHEIMER'S AND OTHER DEMENTIAS - THE BASICS

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## **RISK FACTORS: AGE**

- #I risk factor is advancing age
- Approximately doubles every 5 years after age 65
- I in 3 people age ≥85



21 Alzheimer's Association. *Risk Factors*. Accessed June 8, 2015 from website: http://www.alz.org/alzheimers\_disease\_causes\_risk\_factors.asp 22 Alzheimer's Association, 2015 Alzheimer's Disease Facts and Figures, March 2015

# RISK FACTORS: FAMILY HISTORY, EDUCATION

- Family history
- Hereditary/Genetics
- Education, cognitive engagement

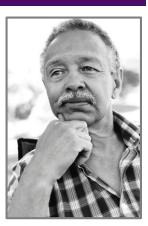


<sup>23</sup> Alzheimer's Association. Risk Factors. Accessed from website: http://www.alz.org/alzheimers\_disease\_causes\_risk\_factors.asp

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## **RISK FACTORS: RACE & ETHNICITY**

- African-Americans: 2 times greater risk
- Hispanics: 1.5 times greater risk
- Cardiovascular risk factors more common
- Lower levels of education, socioeconomic status



<sup>24</sup> Alzheimer's Association (2016) Alzheimer's Disease Facts and Figures

## **RISK FACTORS: WOMEN**

- 2/3 of affected population
- 16% of women age ≥ 71 (11% of men)
- At age 65 have more than I in 6 chance (I in I I for men)
- Age ≥ 60, are twice as likely to develop Alzheimer's than breast cancer



25 Alzheimer's Association, AAIC Press Release, July 21, 2015 26 Alzheimer's Association, Public Health E-News, July 22, 2015

31

# MODIFIABLE RISK FACTORS: HEAD TRAUMA

- Moderate and severe traumatic brain injury
  - o Moderate injury: 2.3 times greater risk
  - Severe injury: 4.5 times greater risk
- Risk remains for years after injury



<sup>27</sup> Alzheimer's Association. (2015) Traumatic Brain Injury.

## MODIFIABLE RISK FACTORS: LIFESTYLE

- Increases risk
  - Current smoking
  - Midlife obesity
- Decreases risk
  - Physical activity
  - Heart-healthy diets: DASH, Mediterranean diet
  - Mental and social activity

<sup>28</sup> Alzheimer's Association. (2014) Alzheimer's and Public Health Spotlight: Heart Health and Brain Health.
<sup>29</sup> Alzheimer's Association. Prevention and Risk of Alzheimer's & Dementia. Accessed July 16, 2015 from website: <a href="http://www.alz.org/research/science/alzheimers\_prevention\_and\_risk.asp">http://www.alz.org/research/science/alzheimers\_prevention\_and\_risk.asp</a>

. .

# MODIFIABLE RISK FACTORS: CARDIOVASCULAR

- Heart-head connection
- Cardiovascular risk factors:
  - o High blood pressure in midlife
  - Heart disease
  - Stroke
  - Diabetes



30 Alzheimer's Association. Prevention and Risk of Alzheimer's & Dementia. Accessed July 16, 2015 from website: <a href="http://www.alz.org/research/science/alzheimers\_prevention\_and\_risk.asp">http://www.alz.org/research/science/alzheimers\_prevention\_and\_risk.asp</a>

## TREATMENT & MANAGEMENT

ALZHEIMER'S AND OTHER DEMENTIAS - THE BASICS

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## **DIAGNOSING ALZHEIMER'S DISEASE**

- No single test
- Medical evaluation
  - Medical history
  - o Mental status testing
  - Information from family and friends
  - o Physical and neurological exams
  - o Rule out other causes



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31 Alzheimer's Association. Diagnosis of Alzheimer's Disease and Dementia. Accessed June 8, 2015 from website: <a href="http://www.alz.org/alzheimers\_disease\_diagnosis.asp">http://www.alz.org/alzheimers\_disease\_diagnosis.asp</a>

## TREATING & MANAGING ALZHEIMER'S

- No cure
- Drug and non-drug treatments
- Primary goals of treatment:
  - o Maintain quality of life
  - Maximize function in daily activities
  - o Enhance cognition, mood, behavior
  - Foster safe environment
  - Promote social engagement



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<sup>32</sup> Alzheimer's Association. *Health Care Professionals and Alzheimer's*. Accessed June 8, 2015 from website: http://www.alz.org/health-care-professionals/medical-management-patient-care.asp

## **ALZHEIMER'S: CO-MORBIDITIES**

- Additional chronic conditions (e.g., heart disease, diabetes, depression)
- Difficult to manage
- Higher rates of hospitalizations and costs
  - o 3 times as many hospital stays
  - o 3 times average Medicare costs
- Preventable hospitalizations



33 Alzheimer's Association. (2013) Combating Alzheimer's Disease: A Public Health Agenda.



# ALZHEIMER'S: UNIQUE ASPECTS

- Financial hardship
  - May lose income and savings
  - o Increased reliance on public programs
- Stigma
- Vulnerability to abuse

34 Alzheimer's Association. Abuse. Accessed July 16, 2015 from website: https://www.alz.org/care/alzheimers-dementia-elder-abuse.asp

# CAREGIVERS ALZHEIMER'S AND OTHER DEMENTIAS – THE BASICS

## ALZHEIMER'S: CAREGIVERS

- Responsibilities:
  - o Dressing, bathing, toileting, feeding
  - Shopping, meal preparation, transportation
  - Medication
  - o Financial management
  - Emotional support
- Increasing levels of care
- Results in complete dependence



<sup>35</sup> Alzheimer's Association. (2015) Alzheimer's Disease Caregivers.

## **CAREGIVERS: CHALLENGES**

- Physical, financial, psychological challenges
  - \$10.2 billion additional annual health care costs (2015)
  - o 60% rate emotional stress as high or very high
  - o 40% suffer from depression



<sup>36</sup> Alzheimer's Association. 2016 Alzheimer's Disease Facts and Figures.

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## **CONCLUSION: KEY POINTS**

- Disease likely develops as result of multiple factors
- Symptoms worsen over time; average lifespan 4-8 years (up to 20)
- Risk factors include: age, family history, head trauma, education, lifestyle, cardiovascular conditions
- African-Americans, Hispanics, women more likely to develop

## **ROLE OF PUBLIC HEALTH**

- 3 key public health intervention tools:
  - Surveillance/monitoring
  - o Primary prevention (risk reduction)
  - o Early detection and diagnosis



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# DEMENTIA CAPABLE SYSTEMS AND DEMENTIA FRIENDLY COMMUNITIES

- Dementia capable systems
  - o Public health research and translation
  - Support services
  - Workforce training
- Dementia friendly communities



# FOR MORE INFORMATION

For more information, please visit the Alzheimer's Association website at: <a href="http://www.alz.org">http://www.alz.org</a>

alzheimer's Sassociation

## **SAMPLE TEST QUESTIONS**

- 1- Dementia is a decline in mental ability that is a normal part of aging.
  - a. True
  - b. False

Answer: B

- 2- The number one risk factor for Alzheimer's disease is:
  - a. Getting older
  - b. High blood pressure
  - c. High cholesterol
  - d. Heredity/genetics
  - e. Lack of mental stimulation

Answer: A

- 3- The more years of education a person has may decrease his/her risk for getting Alzheimer's disease.
  - a. True
  - b. False

**Answer:** A

- 4- The lifespan for someone after being diagnosed with Alzheimer's can be up to 20 years.
  - a. True
  - b. False

**Answer:** A

- 5- Which of the following statements is true about Alzheimer's disease:
  - a. Can be diagnosed through a blood test
  - b. Is a progressive disease
  - c. Is reversible with proper medication
  - d. All of the above
  - e. None of the above

Answer: B

## **Selected Case Studies- Module 2**

On the suggested video resources list, there are several well done documentaries that cover various aspects of Alzheimer's and its impacts on individuals and families. Several of the suggested videos are used as case studies with discussion questions that can be used in class or as an outside assignment.

The case studies are designed to be used in conjunction with the article or video listed. The program title, run time, web link, keywords, relevance to modules, a program description and discussion questions are listed for each piece.

It is recommended that the audio/video be used in conjunction with the discussion questions. However, if time and/or internet access is limited, each case study has a summary that provides enough information to generate discussion or conversation without having to view the video.

# 1- "Inside Alzheimer's: What's it like to live with early-onset Alzheimer's disease? Greg O'Brien offers a glimpse," NPR special series (2015).

- Audio/Transcript Link: <a href="http://www.npr.org/series/389781574/inside-alzheimers">http://www.npr.org/series/389781574/inside-alzheimers</a>
- Run Time:4-6 minutes per segment (audio)
- Key Terms: progression, younger-(early) onset, cancer, long term care, end
  of life decisions, caregiver burden, spouse/partner relationship, family
  relationship, loss of appetite, loss of smell, loss of taste, hallucinations,
  medications, GPS app, loss of identity
- Modules: 1, 2, 4

## **Description:**

A nine part series of articles and audio clips that chronicle aspects of one man's journey with Alzheimer's disease; audio clips are 4-6 minutes each.

Writer Greg O'Brien was diagnosed with younger-onset Alzheimer's disease six years ago when he was 59 years old. Not only was he diagnosed with younger-onset Alzheimer's disease, but he was also diagnosed with stage-three prostate cancer a few years later. Greg is a journalist and writer living in Cape Cod with his wife, Mary Catherine, and their three children. Greg began demonstrating signs of Alzheimer's disease, such as memory loss and getting lost as his own mother was in the end stages of Alzheimer's.

Mary Catherine says that Alzheimer's disease changed Greg's personality in many ways. On one hand, Greg discusses certain topics with her more openly than he would have in the past, but she also has noticed that he gets angry now, something he never used to

do before. In the past, Greg was a loud, outgoing man who was often was at the center of discussion. Now he is quieter and more solitary, even disappearing into a different room when crowds of visitors become overwhelming for him. Greg also used to run upwards of six miles daily as a part of his daily routine; however, he began getting lost and switched to running in a gym.

Greg's personality is not the only thing that has changed since his younger-onset Alzheimer's diagnosis. Greg's appetite and sense of taste and smell have declined. Greg says that food now often tastes the same, like "rolled up newspaper." Greg does buy fruit bars and states that although they have no taste, they do feel cold, which is a different and enjoyable sensation.

As Greg's Alzheimer's disease has progressed over the past six years, so have his hallucinations. Hallucinations are a rarely discussed aspect of Alzheimer's disease but can often accompany memory loss. According to Greg's doctors, these hallucinations are due to the changes in his brain as a result of the disease.

Mary Catherine and Greg's outlook on life has also changed over time. For example, Mary Catherine says that she no longer can get impatient, which is difficult, but important. In the beginning of his diagnosis, Greg used to get very angry, but now he no longer does as he tries to focus in the moment instead of the past or future. Mary Catherine believes their marriage has gotten even stronger as they navigate Greg's Alzheimer's disease.

Because of Greg's Alzheimer's, Greg and Mary Catherine have had to make many difficult decisions, including deciding to sell their house that Greg built, where they raised their three children and planned to grow old together. Growing old in that house together is no longer a realistic possibility, due to Greg's Alzheimer's disease.

Greg, Mary Catherine, and his physician have discussed "exit strategies" for Greg while he is still aware and able to make these types of decisions. One of these exit strategies includes not treating his stage three prostate cancer. Greg's physician says that not treating the prostate cancer will most likely shorten his life, but Greg is okay with this because he would rather his life be shortened by the prostate cancer than by the Alzheimer's disease. Greg states that he is most afraid of the "in-between;" he loves living and he is not afraid to die, but he fears the middle portion, the loss of identity and independence, and dreads his family's suffering as they watch his slow decline.

## **Discussion Questions:**

• Why is it important that individuals with Alzheimer's disease are diagnosed early?

- When individuals are exhibiting signs of Alzheimer's disease, the people around them need to understand what is happening so they can be patient and react in an understanding way.
- Being able to make important decisions about their care, including at the end of life, and finances while they are still able to make informed decisions.
- What are ways that Greg can maintain his independence as his Alzheimer's disease progresses?
  - Going to the gym worries his family in case he gets lost on the way. A
     GPS app on his phone can alert his family to his location.
- Discuss the importance of end of life planning and role of public health in encouraging people to make plans.
- Discuss the importance of a strong social network and family support.
  - In one of the interviews, Greg talks about how where he lives is a small town where everyone knows everyone and their business. As word of his Alzheimer's disease spread and more people in his town knew about it, people eventually began introducing themselves to him when they began a conversation in order to help him identify them.
- Discuss the advantages and disadvantages of deciding not to treat stagethree prostate cancer as Alzheimer's disease progresses.

# 2- "Can Technology Ease the Burden of Caring for People with Dementia?" NPR (2015).

- Audio/Transcript Link: http://www.npr.org/templates/transcript/transcript.php?storyId=417205451
- Run Time: 4:35 minutes (audio)
- **Key Terms:** care givers burden, financial burden, healthcare system, family support, technology, monitoring systems, long term care
- Modules: 1, 2, 3, 4

#### **Description:**

Aurora is 78 years old and lives with her husband, Arturo, in a small apartment in San Rafael. Aurora's daughter, Maria, comes by their apartment almost daily to help her mother bathe, grocery shop, do laundry, provide medical care, and do many other things around the house to help her father and care for her mother.

Early in her Alzheimer's disease diagnosis, Aurora began wandering at night. Afraid that she might wander into the street, Arturo, began sleeping on the floor in front of the bedroom door in order to keep Aurora from leaving the apartment. Maria had the idea

of attaching wind chimes to the door so that Arturo can hear when the door is opened and closed.

Maria and Arturo are currently able to provide all the necessary care for Aurora to live safely in her own home. However, caring for patients with Alzheimer's disease is mentally and financially exhausting. As Aurora's Alzheimer's disease progresses, her safety in the apartment becomes an increasing concern.

The story discusses ways that technology such as remote sensor monitoring systems can help people with dementia stay independent longer while giving caregivers a way to monitor activity and safety.

## **Discussion Questions:**

- What are some technologies available to help monitor the health of people diagnosed with Alzheimer's disease?
  - Temperature sensor on stoves, Bluetooth blood sugar meters, sensor monitoring systems
- What are ethical dilemmas about these kinds of technologies that may be considered invasive of an individual's privacy and health?
  - These types of technologies could perhaps prolong independence and delay entering care facilities by allowing for close, consistent, and constant health and safety monitoring
  - Allows for peace of mind for family members who may not be able to visit daily
  - Sensor Monitoring Systemshttp://www.cnn.com/2014/08/25/tech/innovation/alzheimers-smarthome/ allows caregivers to keep a close watch on their loved ones with Alzheimer's disease through monitoring systems in the house that send notifications to the caregiver's smartphone
  - Some people with Alzheimer's disease say they feel better and safer knowing their family members are able to interact with them and monitor their safety even though they may live far away
- What are other ideas for technology that will allow for increased safety and prolonged independence of older adults with Alzheimer's disease?
- What is the role of public health with assistive technologies?
  - Possible roles: safety reviews and regulation, consumer education, policy development on ways to help make technology affordable for lowincome families, addressing ethical challenges

# 3- "Alzheimer's Long and Costly Goodbye-Heartache and Hope: America's Alzheimer's Epidemic (Episode 1)," University of California Television (2012).

Video Link:

http://myuctv.tv/2012/09/18/alzheimers-the-long-and-costly-goodbye/

• Run Time: 12:30 minutes

• **Key Terms:** stigma, loss of identity, increasing prevalence, increasing aging population, caregiver's burden, family relationships, financial burden

• Modules: 1, 2, 3, 4

## **Description:**

This documentary discusses how Alzheimer's disease affects the lives of individuals and families, touching on concepts from daily tasks becoming difficult or impossible, to the loss of self-identity that occurs. Often receiving an Alzheimer's diagnosis creates an emotional, physical, and financial impact on not only the individual diagnosed, but also family members and friends. This documentary also describes the economic impact of Alzheimer's in the US and on the health care system, as well as its increasing prevalence as the aging population continues to increase around the globe. This documentary provides multiple real-life Alzheimer's examples, such as President Reagan's diagnosis and decline through an interview with his daughter, and Leeza Gibbon's struggle with caring for her mother who lived with Alzheimer's disease for 10 years. Experts also discuss Alzheimer's financial burden on individuals, families, and the US economy, as well as other countries. This documentary briefly mentions the National Plan to Address Alzheimer's Disease.

## **Case Study: Patti**

Patti graduated as the valedictorian of her high school and a few years later, she graduated magna cum laude from Syracuse University. Patti was a successful professor at a university for many decades. A few years ago, Patti began having difficulty remembering how to do simple daily tasks, such as making coffee, and she was constantly losing her glasses, her phone, or other items. Patti never told anyone about her memory issues because she thought it was embarrassing to admit that she was getting older. However, recently, Patti was diagnosed with Alzheimer's disease. Now, Patti describes the difficulty of doing simple tasks as if a voice in her head is constantly challenging her, saying, "How do you do that?" Now, daily activities leave Patti lost and confused. Patti often finds herself turning around in circles as she tries to remember or figure out how to do.

Patti planned on leaving an inheritance for her son when she passed away. Patti has a reverse mortgage, which is a special type of home loan for older adults that allows them to convert a portion of the equity of the home into cash. Older adults often use the cash payments to supplement income from Social Security, for unexpected medical expenses,

home improvements, and many other uses. Alzheimer's disease is a costly disease. Patti now worries that she will no longer be able to leave an inheritance for her son because she could be drained of all her finances to cover her care needs.

## **Discussion Questions:**

- Consider the costs that are associated with medical care and long-term services for people with dementia. What kinds of financial protections are in place to protect older adults' finances who live on a fixed income?
- What are other countries doing to provide quality and affordable medical care to their older adults?
- How does financial planning play a role in preparing for aging, potential onset of illnesses or disability, and the associated costs of care?

## **Alzheimer's Disease Video Resources**

The following videos are listed as suggested accompaniments to the curriculum modules. These could be shown in class or as suggested viewing outside of class.

## **1- "Inside the Brain: An Interactive Tour,"** Alzheimer's Association (n.d.).

• Tour Link: http://www.alz.org/alzheimers disease 4719.asp

• Run Time: N/A

• **Key Terms:** Alzheimer's disease, brain activity, neurotransmitters, amyloid plaques, tangles

• Modules: 1, 2

## **Description:**

This interactive tour helps explain the basic components of the brain and how Alzheimer's disease affects it. The tour teaches the participant the different parts of the brain, how Alzheimer's disease damages the brain and brain activity, and the different stages of the disease.

## 2- "What is Alzheimer's disease?," TedEd (n.d.).

• Video Link: https://www.youtube.com/watch?v=yJXTXN4xrl8

• Run Time: 3:49 minutes

• Key Terms: stages of Alzheimer's, pathology of Alzheimer's

• Modules: 1, 2

## **Description:**

Alzheimer's disease is the most common cause of dementia, affecting over 40 million people worldwide. Though it was discovered over a century ago, scientists are still searching for a cure. Ivan Seah Yu Jun describes how Alzheimer's affects the brain, shedding light on the different phases of this complicated, destructive disease.

# **3- "Heartache and Hope: America's Alzheimer's Epidemic,"** University of California Television (2012).

• Video Link: http://www.uctv.tv/alzheimers/

• Run Time: approximately 12 minutes each

 Key Terms: stigma, increasing prevalence, clinical trials, research, caregiver's burden, family relationships, financial burden

• Modules: 1, 2, 3, 4

## **Description:**

This three-part series reveals the heartache for those suffering from and coping with Alzheimer's disease and the hope offered by UCLA researchers leading the charge to slow its progress and, eventually, find a cure. The series also profiles a growing network of caregiver support groups established by Patti Davis, daughter of

President Ronald Reagan, and television personality Leeza Gibbons, who lost her mother to the disease.

- a) Alzheimer's Long and Costly Goodbye Heartache & Hope: America's Alzheimer's Epidemic (Ep. 1)
  - Video link: <a href="http://myuctv.tv/2012/09/18/alzheimers-the-long-and-costly-goodbye/">http://myuctv.tv/2012/09/18/alzheimers-the-long-and-costly-goodbye/</a>
  - o Run time: 12:30 minutes
  - o **Key terms:** dementia, diagnosis, cost
  - Description: As Baby Boomers become senior citizens, Alzheimer's Disease and other forms of dementia are on track to reach epidemic proportions, with a new case every 68 seconds and an annual cost of \$1.2 trillion projected by 2050. The disease also takes its toll on family members struggling to care for their loved ones, while watching them slowly slip away in what some describe as "the long goodbye." The first in a series of three programs from UCLA offers an overview of the looming epidemic and illustrates the fear and grief experienced by patients and their loved ones, including Patti Davis, daughter of Ronald Reagan, and TV personality Leeza Gibbons, who lost her mother to Alzheimer's.
- b) Alzheimer's Diagnosis and Clinical Trials Heartache & Hope: America's Alzheimer's Epidemic (Ep. 2)
  - Video link: <a href="http://www.uctv.tv/shows/Alzheimers-Diagnosis-and-Clinical-Trials-Heartache-Hope-Americas-Alzheimers-Epidemic-Ep-2-23979">http://www.uctv.tv/shows/Alzheimers-Diagnosis-and-Clinical-Trials-Heartache-Hope-Americas-Alzheimers-Epidemic-Ep-2-23979</a>
  - o Run time: 12:26 minutes
  - Key terms: research, clinical trials
  - Description: The projections for Alzheimer's disease and other forms of dementia are alarming, but not all the news is bad. The second installment in this series from UCLA assesses the progress researchers have made in understanding the disease and highlights some promising clinical trials and diagnosis techniques that could slow its progression, possibly the first step towards prevention and cure.
- c) Alzheimer's Patient and Caregiver Support Heartache & Hope: America's Alzheimer's Epidemic (Ep. 3);
  - Video link: <a href="http://www.uctv.tv/shows/Alzheimers-Patient-and-caregiver-Support-Heartache-Hope-Americas-Alzheimers-Epidemic-Ep-3-23981">http://www.uctv.tv/shows/Alzheimers-Patient-and-caregiver-Support-Heartache-Hope-Americas-Alzheimers-Epidemic-Ep-3-23981</a>
  - o Run Time: 12:26 minutes
  - Key Terms: caregiver support, patient support, resources

Description: It's often said, "If you've seen one person with Alzheimer's, then you've seen one person with Alzheimer's." The disease affects everyone differently, but all patients and their families experience some form of grief and fear, not to mention the stress put on the caregivers. The third and final installment in this series from UCLA offers up new models for healthcare and caregiver support that emphasize early diagnosis and support networks for everyone touched by the disease, including Patti Davis, daughter of Ronald Reagan, and TV personality Leeza Gibbons, who lost her mother to Alzheimer's.

## **4- "Caregivers,"** HBO (n.d.).

- Video Link: <a href="http://www.hbo.com/alzheimers/caregivers.html">http://www.hbo.com/alzheimers/caregivers.html</a>
- Run Time: 48:48 minutes (each segment is approximately 10 mins)
- Key Terms: stigma, caregiver relationship, life after caregiving, duties and responsibility, assisted living facilities
- Modules: 1,3,4

#### **Description:**

This documentary shares the stories of 5 caregivers and demonstrates the struggle and resilience of the caregiver when a family member is diagnosed with Alzheimer's disease. These caregivers struggle to balance their own lives and responsibilities with the daily duties and responsibilities of caring for a loved one with Alzheimer's disease. This documentary illustrates the many challenges and sacrifices of a caregiver, such as personal responsibilities and the social stigma of caring for a loved one whether in their family home or in professional medical facilities.

# 5- "Inside the Brain: Unraveling the Mystery of Alzheimer Disease," National Institutes of Health, NIH Senior Health (n.d.).

- Video Link:
   http://nihseniorhealth.gov/alzheimersdisease/whatisalzheimersdisease/video/a
   2 na.html?intro=yes
- Run Time: 4:21 minutes
- Key Terms: neurobiology of Alzheimer's disease, the brain, cellular circuitry, cellular communication, neurotransmission, beta amyloid plaque formation, neurofibrillary tangle formation
- Modules: 1, 2

**Description:** This short video compares healthy, functioning cellular brain communication with the biological mechanism of plaque and neurofibrillary tangle formation in a brain of someone that has Alzheimer's disease.

# 6- "Understanding the Selfhood of People with a Dementia: Context Is Key," Dr. Steven Sabat and Dementia Alliance International (2015).

• Video Link: https://www.youtube.com/watch?v=3XxY7kMRSvk

• **Run Time:** 68 minutes

• Key Terms: dementia, selfhood, communication, caregivers

Module: 2Description:

Professor Steven R. Sabat of Georgetown University has studied the intact cognitive and social abilities (including aspects of selfhood) of people with Alzheimer's disease in the moderate to severe stages of the disease, the subjective experience of having the disease, and the ways in which communication between those diagnosed and their caregivers may be enhanced. In this presentation for the Dementia Alliance International, A Meeting of the Minds Webinar, Dr. Sabat discusses three lenses -- biomedical, existential-phenomenological, and bio-psychosocial -- for understanding and interacting with a person with dementia, including Alzheimer's. Each lens can provide insights into the effects of dementia on a person and how the individual reacts to those effects. The video emphasizes the importance of personal history and respect for selfhood. Dr. Sabat suggests ways to help people living with dementia cope with their experiences.

## **7- "The Memory Loss Tapes,"** HBO (n.d.).

- Video Link: <a href="http://www.hbo.com/alzheimers/memory-loss-tapes.html">http://www.hbo.com/alzheimers/memory-loss-tapes.html</a>
- Run Time: 85 minutes (divided into 10-12 minute segments)
- Key Terms: family relationship, caregiver relationship, Alzheimer's medications, individual acceptance, family acceptance, assisted living facilities, end of life planning
- Modules: 1, 3, 4

## **Description:**

This documentary gives a short glimpse into the lives of seven individuals in varying stages of Alzheimer's disease. While each diagnosis is different, all of the diagnosed individuals and surrounding family members and caregivers in this documentary are affected by the diagnosis. Central themes in this documentary include, loss of independence, confusion, fear and anxiety, and the importance of support and community resources.

- **8- "What is Alzheimer's Disease?"** National Institutes of Health, NIH Senior Health (n.d.).
  - Video Link:
     <a href="http://nihseniorhealth.gov/alzheimersdisease/whatisalzheimersdisease/video/a">http://nihseniorhealth.gov/alzheimersdisease/whatisalzheimersdisease/video/a</a>
     6 na intro.html

• Run Time: 2:29 minutes

• **Key Terms:** biology and behavioral changes of Alzheimer's disease

• Modules: 1, 2

## **Description:**

This short clip discusses some background information about Alzheimer's disease and explains some of the behavioral changes that occur in diagnosed individuals as the disease degenerately progresses.

# 9- "A Different Visit: Montessori-Based Activities for People with Alzheimer's/Dementia," Center for Applied Research in Dementia (2012).

Video Link: https://www.youtube.com/watch?v=FLDwzgRTbVA

• **Run Time:** 8:07 minutes

• **Key Terms:** caregivers, emotional health, meaningful visits

• Modules: 1, 2, 3

## **Description:**

This clip gives suggestions about how to have a meaningful visit with someone who has been diagnosed with Alzheimer's disease. The video emphasizes focusing on positive feelings. If conversation is not an option, do a simple, safe activity by focusing on the individual's interests and abilities. The most important thing is for the individual to feel good about the visit at the end. The first half of the clip is applicable to Alzheimer's disease, and the second half discusses the theory behind their suggestions (Montessori-based activities).

# 10- "Grandpa, Do you know who I am?" The Alzheimer's Project on HBO (2016).

• **Video Link:** <a href="http://www.hbo.com/alzheimers/grandpa-do-you-know-who-i-am.html">http://www.hbo.com/alzheimers/grandpa-do-you-know-who-i-am.html</a>

• Run Time: 30:48 minutes

• **Key Terms:** children, family, impact of disease on family

• Modules: 1, 4

## **Description:**

This film tells five stories of children, ages 6-15, who are coping with grandfathers or grandmothers suffering from Alzheimer's disease. Maria Shriver provides commentary and delivers valuable "lessons" for the kids, urging them not to blame themselves for what their grandparents do or say. "We are all children of Alzheimer's," says Shriver, sympathetically making it clear that "if it's too painful to visit, you don't have to go." Maria's own father, Sargent Shriver, suffers from the

disease; comparing his earlier vitality to his present condition is hard, but it is offset by good memories and an unexpected "gift": bonds between generations that may not have been made otherwise. Ultimately, the film shows how important it is to "go with the flow," offering up a variety of perspectives on how kids can handle a grandparent's loss of memory through kindness, patience, and compassion.

## 11- "The Supplemental Series," The Alzheimer's Project on HBO (2016).

- Video Link: <a href="http://www.hbo.com/alzheimers/the-supplementary-series.html">http://www.hbo.com/alzheimers/the-supplementary-series.html</a>
- **Key Terms:** Research, genetics, biology, treatment, disease progression, risk factors
- Modules: 1, 2, 3

## **Description:**

The Supplemental Series is a list of 15 videos highlighting a various aspect of Alzheimer's disease:

- a) "Understanding and Attacking Alzheimer's"
  - o Run Time: 12:26 minutes
  - o Key Terms: biology, beta-amyloid protein, plaque, treatments
  - Description: This clip takes a close look at beta-amyloid protein which causes plaque and leads to Alzheimer's disease. This clip focuses on betaamyloid protein research and potential treatments to slow down Alzheimer's progression or even create a vaccine.
- b) "How Far We Have Come in Alzheimer's Research"
  - o Run Time: 15:18 minutes
  - o **Key Terms:** treatment, research
  - Description: This clip discusses the rapid progress in Alzheimer's development and treatment research.
- c) "Identifying Mild Cognitive Impairment"
  - o Run Time: 20:41 minutes
  - Key Terms: research, disease progression, mild cognitive impairment, genetic/family inheritance, cognitive impairment tests, types of cognitive impairment, amnestic form, non-amnestic form, cognitive profile
  - Description: This researcher studies people with mild cognitive impairment and how this progresses over time, as well as how to distinguish between the various different types of cognitive impairment diseases from early signs.
- d) "The Role of Genetics in Alzheimer's"
  - o Run Time: 14:18 minutes

- Key Terms: disease causation, genetics, genetic mutation/alteration, younger-onset, late onset, beta-amyloid plaque, inherited genes, susceptibility gene, sequencing, genetic predisposition
- Description: These two researchers discuss primarily the genetic mutation in the beta-amyloid gene that can lead to younger-onset Alzheimer's disease.

## e) "Advances in Brain Imaging"

- o **Run Time:** 13:13 minutes
- Key Terms: brain imaging (MRI, fMRI), brain shrinking, hippocampus, precuneus, hyperactivity, treatment, vaccines
- Description: This scientist studies how the brain fails during Alzheimer's disease using brain imaging to look at the function, structure, and pathology of the brain.

## f) "Looking into the Future of Alzheimer's"

- o **Run Time:** 10:07 minutes
- Key Terms: increasing aging population, age profile
- Description: This expert discusses the risk factors for Alzheimer's disease, its prevalence, and its increasing presence in public health around the world.

## g) "The Connection Between Insulin and Alzheimer's"

- o Run Time: 21:50 minutes
- Key Terms: insulin resistance, insulin resistance as a risk factor, research, treatment, fat, diet, beta amyloid plaque accumulation and high saturated fat intake, insulin and memory, hippocampus, frontal lobe, intranasal insulin treatment
- Description: This researcher discusses the evidence that insulin resistance (diabetes) may contribute to developing Alzheimer's disease through diet and insulin levels in the brain.

## h) "Inflammation, the Immune System, and Alzheimer's"

- o Run Time: 29:23 minutes
- Key Terms: inflammation in the brain, brain samples, brain cells as living targets, vaccines, mouse models, microglia
- Description: This scientist explains how inflammation affects the brain and can destroy parts of the brain and the nerve fibers over time, leading to Alzheimer's disease. These scientists also describe research that focuses on destroying the beta-amyloid plaque that builds up in the brain that causes Alzheimer's disease to create an effective vaccine using immunotherapy.

## i) "The Benefit of Diet and Exercise in Alzheimer's"

o Run Time: 16:46 minutes

- Key Terms: lifestyle modifications, oxidative damage, antioxidant rich diet, dog model, exercise, BDNF protein, mouse models
- Description: This scientist examines how lifestyle modifications, primarily an antioxidant rich diet and exercise, can affect and even reduce the risk of Alzheimer's disease by studying oxidative damage in the brain.

# j) "Cognitive Reserve: What Religious Orders Study is Revealing about Alzheimer's"

- o Run Time: 22:14 minutes
- Key Terms: memory tasks, brain activity, brain imaging, brain regions,
   brain reserve, Religious Orders Study, brain shrinkage, cognitive reserve
- Description: This clips shows the difference in brain MRIs between the brains of an aging adult with no signs of Alzheimer's disease, an older adult with the brain pathology of Alzheimer's disease that is not yet cognitively impaired, and the brain of an older adult with progressive Alzheimer's disease. This clips also details the work of the Religious Orders Study that studies the progression of Alzheimer's disease as it affects the brain with a goal of how to age without memory loss, including the importance of a supportive social network.

## k) "Searching for an Alzheimer's Cure: The Story of Flurizan"

- o Run Time: 31:20 minutes
- Key Terms: drugs, treatment, Flurizan, non-steroidal anti-inflammatory drugs (NSAIDs), beta-amyloid 42, pharmaceutical industry, statistical significance, ethics
- Description: This clip discusses how current Alzheimer's medications only treat symptoms without changing the progression of the disease, but new drugs, specifically Flurizan, are being researched that aim to modify the progress of the disease by reducing the amount of amyloid plaque built up in the brain. This is currently the largest Alzheimer's drug trial which studies the drug's ability to effectively slow down the biological progression of Alzheimer's disease.

## 1) "The Pulse of Drug Development"

- o Run Time: 15:55 minutes
- Key Terms: drugs, pathology, drug development, cleavage beta-amyloid plaque, detection, biomarkers, ethics, clinical trials, natural remedies, lifestyle changes
- Description: This clip discusses how advanced technology is improving the process to develop specific, early use treatment drugs for Alzheimer's disease.

## m) "The DeMoe Family: Early-Onset Alzheimer's Genetics"

o **Run Time: 25:43** minutes

- Key Terms: younger- (early) onset, genetics, family and intergenerational, predisposition, research, long term preparation, caregiver, family relationships, early diagnosis
- Description: This short documentary examines the DeMoe family which has the dominant gene for younger- (early) onset Alzheimer's disease.
   Doctors and researchers are studying the DeMoe family in order to learn more about this genetically inherited form of Alzheimer's disease.

## n) "The Nanney/Felts Family: Late-Onset Alzheimer's Genetics"

- o Run Time: 22:71 minutes
- Key Terms: late onset, research, genes, family, predisposition, early diagnosis, genetic mutation, gene sequencing, genetic background based risk, intergenerational
- Description: This short documentary studies the Nanney/Felts family that
  has the late onset form of Alzheimer's due to a genetic predisposition
  from a mutated gene that affects the beta-amyloid protein.

## o) "The Quest for Biomarkers"

- o Run Time: 17:06 minutes
- Key Terms: biomarkers, research, clinical trials, Pittsburgh Compound B (PIB) amyloid plaques, PET brain scanning, hereditary, spinal fluid, biofluids
- O Description: This video details the search for biological indicators that can be used to identify individuals who are at a higher risk for developing Alzheimer's disease. Earlier detection of Alzheimer's disease could potentially lead to more effective Alzheimer's treatment and cures as well as allow for treatment prior to the occurrence of becoming symptomatic. The search for an indicative biological marker of Alzheimer's disease includes using brain imaging techniques and analysis of proteins in spinal fluid.

# 12-"Charlie Rose Brain Series 2: Generalized Defects in Cognition: Alzheimer's Disease," Charlie Rose (2012).

- Video Link: <a href="http://www.hulu.com/watch/333114">http://www.hulu.com/watch/333114</a>
- Run Time: 54:00 minutes
- Key Terms: Alzheimer's disease, frontotemporal dementia, Alzheimer's progression, biology, genetics, mutations, small animal laboratory model, diagnosis, healthcare, philanthropy, government funding and resources, early diagnosis, treatment, prevention
- Modules: 1, 3, 4

**Description:** 

This Charlie Rose segment features a panel of experts in fields including aging, neurobiology, and medicine. These experts discuss and compare dementia, Alzheimer's disease, and frontotemporal dementia. Dementia and Alzheimer's disease are differentiated and explained in great detail. This video also explains the difference between normal age-related memory loss and Alzheimer's disease, which is not a natural part of aging. The underlying biological mechanism of Alzheimer's disease is explained as well as the genetics behind younger-onset Alzheimer's disease are also explained in the context of family inheritance and risk factors. The experts discuss the advantages and disadvantages of current Alzheimer's drugs and when to administer these drugs. These experts stress the need for drugs that will address the underlying mechanism of Alzheimer's disease, not just treat the symptoms. These experts discuss the impact on the US economy and society, calling for more governmental support and resources for addressing Alzheimer's disease in addition to privately funded resources. These experts unanimously agree that a significant amount of research and progress has been made within the past 25 years surrounding Alzheimer's disease, however a lot more time, money, and research needs to occur to discover and distribute an effective Alzheimer's drug.

## **Programs Available for Purchase**

(Listed in order of most recent production date)

## 1) "Still Alice," Sony Pictures Classics (2014).

• Video Link: http://sonyclassics.com/stillalice/

• Run Time: 101:00 minutes

• **Key Terms:** Alzheimer's disease, academia, family relationships, end of life planning, younger-onset

Purchase Price:

Digital Download (Amazon): \$12.99

DVD (Amazon): \$12.59

## Description:

A blockbuster movie featuring Oscar-winning actress Julianne Moore, based on the book of the same title. Still Alice is the story of Alice Howland, a renowned linguistics professor, happily married with three grown children, who starts to forget words. When she receives a diagnosis of younger-onset Alzheimer's disease, Alice and her family find their bonds thoroughly tested. Her struggle to stay connected to who she once was is frightening, heartbreaking, and inspiring.

## 2) "Glen Campbell: I'll Be Me," PCH Films (2014).

• Video Link: http://virgil-films.myshopify.com/products/glen-campbell-ill-be-me

• Run Time: 116:00 minutes

• **Key Terms:** progression, music therapy, family

Purchase Price:

Digital Download \$14.99

o DVD \$11.99

## **Description:**

In 2011, music legend Glen Campbell set out on an unprecedented tour across America. He thought it would last 5 weeks; instead it went for 151 spectacular sold out shows over a triumphant year and a half. What made this tour extraordinary was that Glen had recently been diagnosed with Alzheimer's disease. He was told to hang up his guitar and prepare for the inevitable. Instead, Glen and his wife went public with his diagnosis and announced that he and his family would set out on a "Goodbye Tour." The film documents this extraordinary journey as he and his family attempt to navigate the wildly unpredictable nature of Glen's progressing disease using love, laughter and music as their medicine of choice. Special appearances include Bruce Springsteen, The Edge, Paul McCartney, Blake Shelton, Keith Urban, Brad Paisley, Taylor Swift, Steve Martin and Chad Smith among many others.

## 3) "The Sum Total of Our Memory," Barbara Klutnis (2014).

Video Link: http://thesumtotalmovie.com/

• Run Time: 57:00 minutes

Key Terms: family relationship, recent diagnosis, stigma, clinical trials, healthcare

• Purchase Price: \$31.00

#### **Description:**

Couples affected by a partner's recent diagnosis of younger-onset Alzheimer's come to terms with their changing roles. Prominent Alzheimer's medical experts offer their perspectives on diagnosis, the nature of the disease, helpful attitudes in caring for loved ones, stigma, clinical trials, support for caregivers, and overall healthcare concerns.

## 4) "Alive Inside," M. Rossato-Bennett (2014).

• Video Link: <a href="http://www.theconnextion.com/aliveinside/aliveinside">http://www.theconnextion.com/aliveinside/aliveinside</a> index.cfm

• Run Time: 78:00 minutes

• Key Terms: music, memory loss, healing

• Purchase Price: \$14.99

#### **Description:**

Depicts the power of music listening to revitalize and soothe the human spirit in persons with memory loss. Contains interviews with Oliver Sachs and Bobby McFerrin. Won the 2014 Audience Award at the Sundance Film Festival.

## 5) "First Cousin Once Removed," Alan Berliner (2013).

Video Link: http://www.hbo.com/documentaries/first-cousin-once-removed

Run Time: 27:00 minutesKey Terms: progression

• Purchase Price: HBO subscription

## **Description:**

Edwin Honig is a distinguished poet, translator, critic, teacher, honorary knight, and cousin and mentor to the filmmaker, Alan Berliner. Shot over five years for HBO, First Cousin Once Removed documents Honig's experience with Alzheimer's through conversations with family and friends. Berliner captures Honig's literary skills, playfulness and poetic soul, obvious even through his cognitive impairment.

# 6) "Forgetting (the): A Portrait of Alzheimer's: Stories of Love, Courage, and Hope," Twin Cities Public Television, Inc. (2013).

• **Video Link:** <a href="http://www.shoppbs.org/product/index.jsp?productId=1450826">http://www.shoppbs.org/product/index.jsp?productId=1450826</a>

• Run Time: 90:00 minutes

 Key Terms: family, symptoms, treatment options, research, coping, community resources

• Purchase Price: \$19.99

## **Description:**

A PBS documentary with experts Steven DeKosky and Rudolph Tanzi that follows several research studies and the lives of families affected by the disease. Includes a panel discussion of nationally recognized experts led by David Hyde Pierce. This discussion covers symptoms, treatment options, research, coping, community resources, and more.

# 7) "14 Days with Alzheimer's: A Film By Lisa Cerasoli," Lisa Cesrasoli (2012).

Video Link: <a href="http://www.amazon.com/14-Days-Alzheimers-Film-Cerasoli/dp/1589850998/ref=sr 1 1?s=movies-tv&ie=UTF8&qid=1427304005&sr=1-1&keywords=14+days+with+alzheimer%27s">http://www.amazon.com/14-Days-Alzheimers-Film-Cerasoli/dp/1589850998/ref=sr 1 1?s=movies-tv&ie=UTF8&qid=1427304005&sr=1-1&keywords=14+days+with+alzheimer%27s</a>

• Run Time: 29:00 minutes

• **Keywords:** caregiver burden, family relationship

• Purchase Price: \$9.99

## Description:

Winner of the Audience Choice Award at the Life and Death Matters Film Festival, Boulder, Colorado. Based on the memoir, *As Nora Jo Fades Away*, this short documentary examines 14 days in the life of the filmmaker's grandmother.

# **8)** "Bob and Nancy: Inside the Emotions of Alzheimer's," Video Press (2012).

Video Link: <a href="http://www.amazon.com/Bob-Nancy-Inside-Emotions-Alzheimers/dp/B009WSBKGO">http://www.amazon.com/Bob-Nancy-Inside-Emotions-Alzheimers/dp/B009WSBKGO</a>

• Run Time: 20:00 minutes

• Key Terms: progression, family, partner

• Purchase Price: \$50.00

## **Description:**

The progression of Alzheimer's is documented in *Bob and Nancy* through interviews by Peter Rabins who probes the emotions and responses that impact Nancy's life.

## 9) "Caregiver Wellness," Medifecta (2012).

• **Video Link:** <a href="http://www.medifecta.com/dvd-training-programs/caregiver-wellness/">http://www.medifecta.com/dvd-training-programs/caregiver-wellness/</a>

Run Time: 60:00 minutes
Key Terms: caregiver burden
Purchase Price: \$158.99

## **Description:**

Covers the factors of caregiver stress and offers realistic solutions for minimizing stress and nurturing wellness in caregivers. Topics include the importance of maintaining wellness, acknowledging and defusing difficult emotions, using simple and effective exercises for relaxation and renewal, performing activities that foster self-esteem and well-being, and the role of respite.

# 10) "You're Looking at Me Like I Live Here and I Don't," Scott

Krischenbaum & Shane Boris (2012).

Video Link: <a href="http://yourelookingatme.com/">http://yourelookingatme.com/</a>

• Run Time: 54:00 minutes

• **Key Terms:** identity

• **Purchase Price:** \$18.00 (individual license) – 250.00 (colleges/university license)

## **Description:**

Uniquely filmed in an Alzheimer's unit and told from the perspective of an Alzheimer's patient, Lee Gorewitz looks for evidence of her past, her identity, and struggles to remember who she is.

**11) "Dining with Friends: an Innovative Approach to Dining for People with Dementia,"** Alzheimer's Resource Center of Connecticut, Inc &Terra Nova Films (2012).

• **Video Link:** <a href="http://terranova.org/film-catalog/dining-with-friends-an-innovative-approach-to-dining-for-people-with-dementia/">http://terranova.org/film-catalog/dining-with-friends-an-innovative-approach-to-dining-for-people-with-dementia/</a>

• Run Time: 20:00 minutes

 Key Terms: caregiver burden, dining, connections, communication, independence, modified food choices

• Purchase Price: \$99.00

## Description:

Dining with Friends emphasizes how to optimize the dining environment for a dignified experience including the importance of establishing connections between staff and people with dementia, understanding the stages of Alzheimer's disease, how caregivers may develop effective ways to communicate and support independence, and how to easily prepare modified food choices that appetizing and nutritious.

## 12) "Whose Death Is It Anyways?" Christopher Lukas (2011).

- Video Link: <a href="https://www.amazon.com/Whose-Death-Anyway-Nancy-Snyderman/dp/8004TH7BZW?ie=UTF8&keywords=Whose%20death%20is%20it%20anyway%20DVD&qid=1429010157&ref">https://www.amazon.com/Whose-Death-Anyway-Nancy-Snyderman/dp/8004TH7BZW?ie=UTF8&keywords=Whose%20death%20is%20it%20anyway%20DVD&qid=1429010157&ref</a> = \$r\$ 1 2&\$r=8-2
- **Run Time:** 56:00 minutes
- **Key Terms:** end of life care, legal rights, family conflicts, advance directives, palliative comfort care, hospice care, death
- Purchase Price:
  - o Amazon Video \$19.95
  - o Purchase DVD \$39.95-69.95

## **Description:**

A studio audience hosted by Nancy Snyderman, physician and Chief Medical Editor for NBC News, with a live audience including people who have had to make end-of-life decisions. The program examines patients' legal rights, family conflicts about end-of-life care, advance directives, palliative care, and dying at home, in the hospital, or with hospice care.

# 13) "More than Words: A New Culture of Care and Communication with Persons Who Have Dementia," Terra Nova Films (2011).

- Video Link: http://terranova.org/film-catalog/more-than-words/
- Run Time: 25:00 minutes
- **Key Terms:** person centered care, communication
- Purchase Price:
  - Watch On-Demand 24 hours \$19.95
  - Watch On-Demand 2 weeks \$45.00

- o Rent DVD \$59.00
- o Purchase DVD \$179.00

## **Description:**

More Than Words demonstrates how person-centered care and knowledge of residents can reduce dementia related symptoms, such as sundowning, aggressive reactions when bathing, and wanting to leave. Shows valuable tips to redirect and lessen anxieties for persons with dementia while preserving their personal autonomy and dignity. Topics covered include building and maintaining a relationship, dealing with difficult situations, communicating to show respect, accepting their realities, respecting the person's preferences, and encouraging use of remaining abilities.